

ADAPTED DANCE – CONNECTING MIND, BODY AND SOUL

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*Live \* Laugh \* Dance*

## PREFACE

Why adapted dance? My true passion in life has always been dance! In addition to loving dance, I also have always enjoyed working with individuals with disabilities – in particular individuals with intellectual disabilities. Growing up I had an aunt who was mildly cognitively impaired. Although she was 20 years older than me she was still one of my best childhood friends. We had so much fun together and I loved making her smile and laugh. This is what initially sparked my interest in working with individuals with disabilities.

During my undergraduate career I had the privilege of taken Dr. Stanton's course titled Physical Activity Programming for Individuals with Disabilities. As part of this course I was required to participate in a service learning experience where I was paired one-on-one with a client who had a disability. The young lady I was paired with had Down syndrome. I worked with my client once per week as a personal trainer at a local gym. In the beginning I had a very hard time getting her to perform any type of cardiovascular exercise. However, during the 3<sup>rd</sup> or 4<sup>th</sup> week I decided to try aerobic dance in the group fitness studio at the gym. She loved it! From that point on I focused my lesson plans around dance. This experience is what sparked my interest in dance for individuals with Down syndrome.

After searching the literature I realized that not a lot of data exists on dance for individuals with Down syndrome. This is why I chose to create an adapted dance program specifically for adolescents and young adults who have

Down syndrome. The adapted dance program is currently in its second year and is titled the Live Laugh Dance Camp.



## ABSTRACT

Rachel R. Swinford

### ADAPTED DANCE – CONNECTING MIND, BODY AND SOUL

Using Heideggerian interpretive phenomenology, this study illuminates the lived experience of an adapted dance program for individuals with Down syndrome and their family members. The overall pattern from both dancers and family members was adapted dance: connecting mind, body and soul. The primary theme from dancer interpretations was expressing a mosaic of positive experiences, and the primary theme from family member interpretations was experiencing pride in their loved ones. The dance program provided dancers an opportunity to express their authentic self while experiencing moments of full embodiment in the connection of their mind, body and soul. While dancers experienced the connection of mind-body-soul, family members recognized the importance of this connection in their loved one. This research is instrumental in advocating for opportunities for individuals with Down syndrome to experience dance as a social, physical and intellectual activity that results in learning and increasing social interactions. The research findings from this study can support future initiatives for dance programs that may influence a population that has limited access to physical activity and dance. The study's teaching strategies, dance activities, class procedures and sequences, and feedback techniques can be used by other professionals who teach individuals with intellectual disabilities.

Marsha L. Ellett, PhD, RN, CNE, Chair

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## **Chapter I: The Problem**

### Introduction

Down syndrome, medically referred to as Trisomy 21, is a genetic condition that occurs when a baby is born with an extra copy of the 21<sup>st</sup> chromosome. It has been estimated that approximately 1 in every 800 babies are born with Down syndrome each year in the United States, and 1 in 1,000 children and adolescents aged 0-19 years of age have Down syndrome (Sherman, Allen, Bean, & Freeman, 2007; Shin et al., 2009). Individuals with Down syndrome often exhibit commonalities in physical appearance including short stature, small hands and feet, flat feet, and slanted eyes. Additionally it is common for individuals with Down syndrome to experience physiological issues such as atlantoaxial instability (or instability between C1 and C2 vertebrae), hypotonia, and heart and lung problems (Angelopoulou, Tsimaras, Christoulas, & Mandroukas, 1999; Maatta et al., 2011; Pueschel & Scola, 1987). All individuals who have Down syndrome also have some degree of cognitive impairment. However, the level of impairment is very individual and can range from mild to severe as measured by intelligence tests (Fraser & Sadovnick, 1976; Hurley & Sovner, 1982). Therefore, the range of intellectual ability varies on an individual basis.

Individuals with Down syndrome often experience low levels of physical activity that can contribute to both cardiovascular disease (Pitetti,

Rimmer, & Fernhall, 1993) and obesity (Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998). It is also common for individuals with Down syndrome to experience decreased levels of social participation that can lead to a lower quality of life (Heah, Case, McGuire, & Law, 2007). Therefore, physical activity for individuals with Down syndrome is very important, however, it is sometimes a challenge due to potential limitations such as low fitness capacity; balance and coordination issues; extreme range of motion limitations; and trouble reaching their age-predicated maximal heart rate (Balic, Mateos, Blasco, & Fernhall, 2000; Fernhall et al., 1996).

Regardless of limitations, physical activity is still important for individuals with Down syndrome, and a set of guidelines should be followed when programming physical activity or exercise. Adapted physical activity is a term that is often used to describe physical activity that is performed by individuals with disabilities. In simple terms, the addition of the word adapted to physical activity implies that adaptations are being made based on an individual's skills and abilities that focus highly on what an individual can do. In general, adapted physical activity should be structured and made as fun as possible (Mahy, Shields, Taylor, & Dodd, 2010). Many individuals with Down syndrome experience both cognitive and social difficulties; thus, a system of rewards should be set in place for behavior modification when working with individuals who have Down syndrome (Bennett, Eisenman, French, Henderson, & Shultz, 1989). When compared to children without Down syndrome, children with Down syndrome have been found to have more behavioral issues such as attention-deficit, non-compliance, and

social withdrawal (Coe et al., 1999). Despite these problems, social interaction is extremely important for individuals with Down syndrome, and having a behavior modification system in place will help increase adherence to the activity.

Parents of children with Down syndrome also identify the need for physical activity for their children. A recent qualitative study found that parents enjoy seeing their child with Down syndrome participate in physical activity for the following reasons: (a) was a positive influence on health, (b) provided social interaction with individuals with and without Down syndrome, (c) encouraged independence for teenagers and adults when involved in an individual sport, (d) offered community programming for individuals with Down syndrome, and (e) included support for parents from adapted specialists to help increase at-home physical activity (Menear, 2007).

Individuals with Down syndrome benefit from opportunities to increase physical activity as well as social participation. Dance is an activity that can achieve both of these goals. Dance has been explained as a fun and enjoyable physical activity that promotes social interaction and a sense of community (Connor, 2000). Additionally, dance has been shown to increase a variety of physical functions such as balance, strength, and flexibility; it increases overall health; and also has an influence on one's general well-being (Keogh, Kilding, Pidgeon, Ashley, & Gillis, 2009). Therefore, an adapted dance program specifically designed for adolescents and young adults with Down syndrome is

an appropriate activity with the potential for having a variety of positive effects for dancers and for their family members as well.

### Statement of the Problem

It is known that adapted physical activity can be useful in increasing activity levels, and social participation for individuals with Down syndrome (King et al., 2003; Murphy & Carbone, 2008; P. E. Wilson, 2002). However, it is not known how participation in an adapted physical activity, specifically an adapted dance program, is experienced by individuals with Down syndrome and their family members. While professionals view increased physical activity and social interaction as potential positive outcomes for individuals with Down syndrome, no literature exists on what the proposed dancers and their family members actually experience as a result of participation in this type of activity. This qualitative study was developed to understand the potential outcomes that can only be experienced by those who are affected by Down syndrome and their family members. This study provides an insider-out view by seeking the perspectives of individuals who are affected by the condition, rather than using an outsider-in view of seeking the perspectives of professionals in the area.

### Purpose and Significance of the Study

The purpose of this study was to explore the lived experience of participation in an adapted dance program for individuals with Down syndrome and their family members. For this study, there were two specific aims:

1. To illuminate the experience of an adapted dance program as perceived by the dance participants.
2. To illuminate the experience of an adapted dance program as perceived by family members of the dance participants.

These two aims were achieved by conducting one-on-one unstructured interviews with dance participants who have Down syndrome followed by one-on-one telephone or small focus group interviews with their family members. Interpretive phenomenology was the inquiry and analysis method guiding this study.

Understanding the lived experience of an adapted dance program, as perceived by dance participants and their family members, can enhance future physical and social activity opportunities for individuals with Down syndrome. When the dancers and family members were asked for their inside-out view of this activity, light was shed on how adapted dance programs connect mind, body and soul. This in turn can provide previously unrecognized physical, social, and psychological benefits for individuals with Down syndrome. Using a qualitative approach to explore the lived experience of an adapted dance program for individuals with Down syndrome and their family members provides dance instructors, physical educators, and rehabilitation specialists with a deeper understanding of how the dancers and family members view dance experiences, beyond what is objectively measurable. Findings from this study have noteworthy implications for adapted physical activity



specialists. This information is beneficial because physical activity programming for individuals with Down syndrome can sometimes be a problematic (Drum et al., 2009; J. H. Rimmer, Chen, McCubbin, Drum, & Peterson, 2010).

### Scope of the Study/Limitations of the Study

This is an initial study into the previously unrecognized outcomes of adapted dance programs developed specifically for individuals with Down syndrome and their family members. It is limited in the small number of participants and will need replication to strengthen the findings. It is also limited in the age of dance participants and further studies should examine a larger age range.

### Methodology

#### *Heidegger's Interpretative Phenomenology:*

#### *A Philosophical and Methodological Framework*

Interpretive phenomenology was the inquiry and analysis method guiding this study. The goal of interpretive phenomenology is to identify meaning and gain understanding of personal experiences (Lopez & Willis, 2004). Specifically for this study, a Heideggerian view of personhood was the philosophical framework. Martin Heidegger was a 20<sup>th</sup> century German philosopher who viewed phenomenology based on ontology, or the nature of being. He used the term, Dasein, or being-in-the-world, to describe personal meanings of events or

situations for individuals as they inhabit their own unique everyday worlds (Leonard, 1989). Essentially the word Dasein describes a snapshot in time as interpreted by the person having the experience. Heideggerian phenomenology is context specific and highly individual in that each person perceives experiences differently based on their own life's understandings. He believed that individuals are thrown into a world not of their choosing that influences who they are, what they believe, and how they think from the day they are born (Leonard). This has important implications in this study because individuals with Down syndrome are born into a world not of their choosing. From a very young age their disability has some influence on how their world is being formed. Similarly, parents of children with Down syndrome may also experience a change in their world the moment their child with Down syndrome is born.

### *Heidegger's Concept of Personhood*

Heidegger described five characteristics that should be considered when studying human beings (Leonard, 1989). These five characteristics can be classified as what he termed personhood. The first characteristic describes the person as having a world, which implies the world is a meaningful place that we are born into. At birth we are thrown into a world not of our choosing that begins affecting who we are. We are thrown into a specific language and culture, which begins molding us as humans at a very young age. He believed that the world is often overlooked as a taken-

for-granted lived experience of everydayness. In interpretive phenomenology it is essential that the individual's unique world be taken into account, such as being born with Down syndrome or being the parent of a child with Down syndrome, as it is the world that shapes and influences our interpretation of experiences.

Leonard (1989) states "phenomenologically, world is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (pg. 43). Individuals with Down syndrome are not only born into a specific culture, they are also born into a culture of having Down syndrome.

Leonard (1989) describes the second characteristic as "the person as a being for whom things have significance and value" (pg. 45). This statement explains that to understand a person's behaviors or expressions, we must study the person in his/her particular context, as it is only there that the person with Down syndrome or his/her families will find meaning and importance in their experience. The context of interest in this study was an adapted dance program.

The third characteristic describes that a person is self-interpreting (Leonard, 1989). This is important in that it describes how human beings engage in experiences based on their interpretive understanding of things. Therefore, it is important to realize the importance of past experiences such as living with Down syndrome, which influences the future. An example for parents of individuals with Down syndrome would be their child's participation in their first sport. It might be assumed that there is something universal about your child playing a sport for the first time. However, this is most likely not the same experience for parents of children with Down syndrome.

The fourth characteristic describes how the person is embodied, which can be described as bodily intelligence whereas our bodies move in and interpret the world we live in (Leonard, 1989). Further, it is about how the body is part of the experience and/or how a “thing” may be embodied. In the present study, the embodiment of dance and Down syndrome was explored. This is a unique observation because dance itself has been described as an embodying experience (Block & Kissell, 2001). For family members, the embodiment of having a loved one who has Down syndrome can be explained as a rollercoaster of emotions. Some experiences create emotions such as sadness and anger, whereas other experiences create emotions of joy and pride. One mother explains her journey of raising a son [Peter] who has Down syndrome (Maxwell & Barr, 2003).

“...with hindsight the journey has been made easier for us by friends and professionals who took time to listen to what I was saying, knowing I only wanted the best for Peter and attempting to find it for me. By friends who allowed me to cry when I needed, and to rejoice when he achieved some particular goal no matter how small. By the school and its teachers who have kept on working with Peter over the years and watch with satisfaction his achievements. By David [father] and Aymie [sister] who just love Peter for himself, and probably by myself for never giving up and always knowing he would do things eventually” (Maxwell & Barr, 2003).

The fifth characteristic is described as the person in time, which implies the past, present, and future are all intertwined and influence one’s meaning and interpretation of experiences (Leonard, 1989). Therefore, the

dance participants' and their family members' past involvements influenced how they interpreted the adapted dance program.

These five characteristics of personhood are important in understanding the world of adapted dance as experienced by individuals with Down syndrome and their family members. All five of these characteristics were taken into account in the present study, and are further explained in chapter four.

### *Quality Criteria for Interpretive Phenomenology Research*

Within any methodology there will always be validity issues. For interpretive phenomenology there are four criteria that can be used to evaluate a study – (a) trustworthiness, (b) consistency, (c) neutrality, and (d) applicability. Trustworthiness, similar to the quantitative term validity, indicates whether a study provides an accurate description of participants' lived experiences (Leonard, 1989). The first way trustworthiness was accomplished in this study was that the individuals with Down syndrome and their family members were the only people interviewed. Experts were not used to explain this experience; only the individuals who own the experience were interviewed. Trustworthiness was also accomplished in the present study by the researcher acknowledging any preconceived notions and attempting to interview with limited presumptions and an open mind. Furthermore, the researcher did not ask any leading or guided questions during the interviews.

Consistency can be thought of in the same way reliability is used in quantitative research. Consistency is found when the individual narratives

describe similar (though not necessarily identical) perceptions of events or conditions and the meanings of those events or conditions for the individual. This was done in the present study by allowing both dancers and family members to share their own individual stories of participation in the dance program. After all interviews were completed the transcripts were evaluated to find any shared meaning across both dancers and family members. Further, consistency was found in the interpretation of narratives by the researcher, as well as by consensus with the members of the Hermeneutic Circle (i.e. the team of researchers for this study) who found similar understandings in the texts of dancers and family members.

Neutrality is a term used in quantitative work to describe the techniques in methods and analysis that the investigator used to limit biased results, such as control groups, blinded interventions and others. In qualitative work we make no presumption that we can be completely neutral; however, we do claim that we can set our biases aside to allow a new understanding to emerge (Leonard, 1989). For the present study it was imperative that the researcher maintained integrity of the data and avoided imposing her perceptions and understandings. It is important for investigators to examine their own perceptions about an event or situation prior to and throughout the study's progress. Using a team of researchers helps each investigator to identify personal biases and set them aside so that the participants' stories can be heard (Leonard, 1989). For the current study, neutrality was supported with the use of a team of researchers

during data analysis. Furthermore, the researcher sought to set aside all biases and preconceived notions prior to conducting interviews.

Applicability can be thought of the same way generalizability is used in quantitative research. Applicability is used to assess whether the results of the study can illuminate contexts outside of the current study (Leonard, 1989). Another term for applicability is usefulness. This explains whether both the researcher and readers can use the information in their own individual settings. In other words, the results of this study are useful for not only the researcher, but also for the readers who may be able to implement the findings in their own work.

### Summary

Although physical activity is important for individuals with Down syndrome, it can sometime be challenging to create an effective program (Drum, et al., 2009; J. H. Rimmer, et al., 2010). Using Heideggerian interpretive phenomenology, this study illuminates the dance participants' and their family members' lived experience of an adapted dance program. The information was gathered by conducting one-on-one unstructured interviews with dance participants who have Down syndrome followed by one-on-one telephone or small focus group interviews with their family members. Results of this study provide individuals with Down syndrome and their family members, dance instructors, physical educators, and rehabilitation specialists with a deeper understanding of how the dancers and family members view dance experiences, beyond what is objectively measurable.

## **Chapter II: Review of Literature**

### Overview

It has been shown that both physical and social activities influence quality of life for people with Down syndrome (Eria Ping-ying, 2006; Heah, et al., 2007). Although physical activity is important for individuals with Down syndrome, they often participate at lower levels when compared to individuals without Down syndrome (Shields, Dodd, & Abblitt, 2009; Whitt-Glover, O'Neill, & Stettler, 2006). A recent qualitative study identified three barriers and three facilitators to physical activity for individuals with Down syndrome. Participants took part in physical activity when they had support from others, when the physical activity was fun or had an interesting purpose, and when the physical activity was routine and familiar. The reasons for not participating included lack of support, simply not wanting to do physical activity, and/or medical/physiological factors (Mahy, et al., 2010). These findings had an influence on the design of the adapted dance program for the current study. For example, the dance program was designed to be a fun experience, the dancers had support from several volunteers, and every dance class followed the same format/structure.

Dance is an activity that can offer many physical benefits as well as emotional and social benefits (Keogh, et al., 2009). Dance is often used as a physical and psychological therapeutic intervention for people with



disabilities as well as some illnesses such as cancer (Cohen & Walco, 1999). Dance or movement therapy is based on the belief that the emotional, physical, and intellectual health of an individual can be manipulated through changes in movement because personality is directly connected to the way we move (Alpert, 2011). For example, Dupont & Schulmann (1987) investigated the physical effects of a 6-month dance therapy intervention for children with Down syndrome. They found balance significantly improved in the treatment group compared to a control group.

Adapted dance differs from traditional dance in that it can focus on individual skills for a range of varying capabilities. Individuals with Down syndrome often have limited physical and cognitive abilities requiring alterations from standard dance techniques. Adapted dance is common among individuals with a variety of disabilities, including both cognitive and physical impairments (Goodwin, Krohn, & Kuhnle, 2004; Wilson, 2010). A recent qualitative study found that dance and music can be used as avenues to increase social participation for children with intellectual disabilities (Sooful, Surujlal, & Dhurup, 2010). Results of the study showed that music and dance are positive mediums for incorporating individuals with intellectual disabilities into the community.

Although dance is often used as a form of physical activity for individuals with disabilities, adapted dance for individuals with Down syndrome has received minimal attention both quantitatively and qualitatively. This study aims to explore the lived-experience of an adapted dance program, as perceived by dance

participants and their family members using Heideggerian interpretive phenomenology.

### Theoretical Framework

Heideggerian interpretive phenomenology was used as the methodology for this study. Specifically, hermeneutic interpretive phenomenology was the guiding principle for data collection and analysis in this study. Leonard (1989) described “a hermeneutic of Dasein as an interpretive effort through which light is shed on the meaning of being” (pg. 51). The goal of hermeneutics is to understand everyday experiences and to find commonalities in meanings of such experiences. A common term associated with hermeneutics is the hermeneutic circle, which refers to the cyclic interpretation of experiences. It describes how a text cannot be interpreted without understanding all parts such as the background and the specific context of an experience (Leonard).

Using the concept of personhood, this study explored the dance participant’s world as an individual with Down syndrome through his/her experience participating in an adapted dance program. Because dance involves using the body and its movements as the means of experiencing and expressing ideas, concepts, and feelings, it aligns with Heidegger’s embodying characteristic of personhood (Leonard, 1989). The dancers’ lived experience was evidenced through their active participation

throughout the dance program. The family members' lived experience was shown through observation of a loved one in the dance program.

Results of this study reveal future possibilities to improve teaching strategies that accommodate individuals with Down syndrome in dance programs. Gardner, Komesaroff, and Fensham (2008) explored young people's experiences in dance classes and found that the dance classes increased self-confidence, enhanced respect for physical activity, and influenced social relationships. The results of this study reveal similar benefits and experiences for young people with Down syndrome, and benefits were also recognized by their family members.

### Historical Background

Phenomenology can be traced back to the first decade of the 20<sup>th</sup> century (Speziale & Carpenter, 2007). Its emergence can be divided into three distinct phases (a) preparatory, (b) German, and (c) French. The preparatory phase primarily involved the works of two philosophers – Franz Brentano and his student Carl Stumpf. The prominent concept that emerged from this phase was intentionality or the belief that the consciousness is always conscious of something (Speziale & Carpenter).

The German phase consisted of two more philosophers – Edmund Husserl and Martin Heidegger (Speziale & Carpenter, 2007). These philosophers developed the concepts of essences, intuiting, and phenomenological reduction. Essences refer to elements that are related to the true meaning of a

phenomenon and provide a common understanding. Intuiting describes how one should accurately interpret what is meant in the descriptions of phenomena. This is done through what is called imaginative variation, in which a researcher varies the data in as many ways as possible in relation to the description/s of the experience. Phenomenological reduction is a technique that researchers follow when analyzing descriptions about phenomena. Essentially it is a process that attempts to avoid a researcher's biases and preconceived notions (Speziale & Carpenter).

The French phase consisted of three philosophers – Gabriel Marcel, Jean-Paul Sartre, and Maurice Merleau-Ponty--who further developed what is known as embodiment and being-in-the-world (Speziale & Carpenter, 2007). Embodiment describes how one gains access to the world by being consciously aware of being-in-the-world (Speziale & Carpenter). This study explores what it means to be embodied through the experiences of dance for adolescents and young adults with Down syndrome. Although family members do not share the physical activity of embodiment in the adapted dance program, they did have the embodied experiences of pain or joy, for example, as their loved one experienced the adapted dance program.

## Review of Literature

### *Adapted Physical Activity*

Adapted physical activity for individuals with Down syndrome is extremely important for both health reasons and social interaction. Despite this fact, physical activity participation among individuals with Down syndrome is lower when compared to peers without Down syndrome (Carmeli, Ariav, Bar-Yossef, Levy, & Imam, 2012; Whitt-Glover, et al., 2006). This low participation in physical activity decreases even more with age (Brown & Gordon, 1987; Carmeli, et al., 2012). When designing physical activity programs for individuals with Down syndrome, it is important to adapt activities based on individual skills and abilities.

The literature provides several reviews of physical activity participation for individuals with disabilities. Rimmer and Rowland (2008) discuss how there is a critical need for affordable and accessible community-based physical activity programs for individuals with disabilities. Murphy and Carbone (2008) summarize the positive effects physical activity has on individuals with disabilities. For example, adapted physical activity promotes increased health and physical fitness, inclusion into sport and recreational activities, and an overall enhancement of well-being. Parents and healthcare professionals should take note of these benefits and adapted programming should focus on providing inclusive options for individuals with all types of disabilities. If more individuals with disabilities had access to adapted physical activity programming, they would

benefit by increasing their physical and social functioning and ultimately increase their overall quality of life.

Research on Special Olympics participation has shown that the physical activity and social interaction associated with sport participation to be highly beneficial for individuals with cognitive disabilities. For example, a survey of both professionals and parents found that Special Olympics provided an opportunity for social adjustment and life satisfaction for athletes (Klein, Gilman, & Zigler, 1993). Another study found a positive influence on self-worth in the athletes (Weiss, Diamond, Demark, & Lovald, 2003).

Individuals with Down syndrome have an increased risk of limited participation in everyday activities that includes physical activity. It is important to identify barriers and facilitators to physical activity so that programs can be designed to increase participation (Heller, Hsieh, & Rimmer, 2002; King, et al., 2003; Mahy, et al., 2010). Common barriers include lack of support and lack of accessibility. Common facilitators include an activity that is fun and provides social support.

Despite the barriers to physical activity for people with Down syndrome, some do participate successfully in activities when they are made available. For example, two studies published in 2006 interviewed individuals with Down syndrome who demonstrated successful participation in extra-curricular activities, including physical activity. They both found role modeling and parental/caregiver support to be a key factor

in successful participation (Heah, et al., 2007; Li, Liu, Lok, & Lee, 2006). This was taken into account in the present study as the dance program provided modeling from volunteers throughout the dance program.

The promotion of physical activity for individuals with disabilities has gained noteworthy recognition over the past few years. Several researchers have aimed to set specific guidelines for the design of physical activity interventions for people with disabilities, with some guidelines specific for certain disabilities (Drum, et al., 2009; Rimmer, et al., 2010; Stanish & Frey, 2008). Specific guidelines for working with individuals with intellectual disabilities include using motivational strategies and positive reinforcement, using low to moderate intensity activities, making the activity fun and involving social interaction; involving participants in the activity selection, using age-appropriate activities, hosting activities in the community where there is opportunity for inclusion, having plans to modify activities as needed based on the ability levels of all participants, and having an evaluation process that measures activity-specific goals (Stanish & Frey, 2008). All of these criteria were used when designing the adapted dance program for this study and will be further discussed in chapter three.

Chapter one briefly discusses the importance of a behavior modification tool when working with individuals who have Down syndrome. The use of such has been shown to increase compliance and to some degree can help manipulate participation (Bennett, Eisenman, French, Henderson, & Schultz, 1989; Lavay, French, & Henderson, 2007; Lavay, Henderson, French, & Guthrie, 2012). Token

economy systems are a common form of behavior modification used in adapted physical activity. This type of system involves operant conditioning where participants receive positive feedback and/or rewards for desired behavior. In the present study a modified token economy system was used in which participants received a personal folder where dancers checked off accomplished activities (Cone & Cone, 2011). Cone and Cone (2011) explain how this strategy prompts participants to think about what will need to be accomplished during the dance class.

### *Dance*

Alpert (2011) defines dance as “the most fundamental of the arts, involving direct expression through the use of body movements and expressions” (pg. 155). Similarly, Crabtree (2011) defines dance as “an individual and community art form that allows individuals to discover themselves and the world around them, while also learning discipline-based content, knowledge, skills, and application” (pg. 15). She goes on to explain how dance is a physical activity and inclusive art form that can be experienced by all individuals – regardless of ability level.

Dance provides many benefits to one’s health that are similar to benefits of traditional fitness activities such as jogging, biking, or swimming. Dance can provide a total body workout and may influence flexibility, muscular fitness, cardiorespiratory endurance, balance, and joint proprioception (Alpert, 2011; Quin, Frazer, & Redding, 2007). In addition to physical health, dance can also



influence psychological health components such as self-esteem and intrinsic motivation to participate in physical activity (Quin, et al., 2007). Furthermore, dance is a fun activity that may provide better adherence when compared to other fitness activities. In addition to health benefits, dance also provides a social benefit in that dancers communicate with each other when dancing (Alpert, 2011).

A qualitative study of young people involved in dance classes found that dance enhanced respect and appreciation for physical activity and improved confidence in both performing physical activity and interacting in social relationships (Gardner, Komesaroff, & Fensham, 2008). In 2004, another qualitative study explored the experience of individuals using wheelchairs in their dance. Data analysis revealed four themes: (a) unconditional acceptance and a sense of belonging, (b) a dream come true and a sense of accomplishment, (c) beyond the wheelchair or using their wheelchair to express themselves through movement and emotion, and (d) a stronger self both emotionally and socially (Goodwin, et al., 2004). These very meaningful findings are similar to the findings in this study.

A recent study demonstrated that individuals with Down syndrome benefit greatly from a dance program (Jobling, Virji-Babul, & Nichols, 2006). A dance program was designed specifically for individuals with Down syndrome using Rudolf Laban's movement analysis concepts (Laban, 1963). The four components of Laban's movement analysis that were used consisted of time, space, weight, and flow. These four concepts were used to teach dancers a

“language of movement”. To do this, the dance program included activities that allowed dancers to achieve the following: (a) an awareness of body, space, and effort; (b) language of movement; (c) a confidence in movement; and (d) increased participation in physical activity, social interaction, independence, and creative expression (Jobling, et al.). By including activities that focus on these four components, the goal was for dancers to “communicate and interact with their peers, develop skills necessary to problem-solve and learn new movement skills, and develop the capacity for creative expression” (pg. 38).

This study was found after the conclusion of the dance program. However, Laban’s movement analysis guidelines were unknowingly used when planning the adapted dance program for the present study. For example, a warm-up activity was included to help children become aware of their body, a skill building section was also included to help students become aware of their body in space, and dance stations were included to help dancers focus on a variety of things such as dance language, effort awareness, creative expression, and social interaction.

In addition to following the above guidelines, additional special considerations had to be taken into account when planning for the adapted dance program. Cone and Cone (2011) published a very helpful article on teaching strategies for all dance abilities. In their article they discuss several methods that can be used when teaching dance to individuals with disabilities. Additional instructional strategies and dance

activities were found in two dance textbooks (Cone & Cone, 2005; McHugh, 2007). The dance program also utilized several volunteers who served as para-educators, or teaching assistants, to provide one-on-one assistance to a few of the dancers (Cone & Cone, 2011; Davis, Kotecki, Harvey, & Oliver, 2007). Additional considerations are discussed in chapter three.

### Summary

Individuals with intellectual disabilities face significant personal, cognitive and social challenges in their daily lives that may influence social participation and physical activity levels (Stanish & Frey, 2008). Dancing is one way of interacting with others in a social setting that can provide both social participation and physical activity. Dance, as an activity that promotes social interaction and physical activity, offers researchers the opportunity to learn about the person with Down syndrome and their family members' perceptions about dance, physical activity, and social interaction.

For this study an adapted dance program was developed specifically for adolescents and young adults with Down syndrome. Although many individuals with Down syndrome participate in dance, the lived experience of dancing has not been the focus of past research studies. Therefore, this study aimed to explore the lived experience among adolescents and young adults with Down syndrome who participated in an adapted dance program. Furthermore, family members of individuals with Down syndrome were given the opportunity to speak

about the effects an adapted dance program had on the daily lives of their children/sibling.

## **Chapter III: Methodology**

### Introduction

Heideggerian interpretive phenomenology was the inquiry and analysis method used in this study. Interpretive phenomenology aims to identify the meanings of phenomena within a specific context. The phenomenon of interest in this study was dancing in an adapted dance program for individuals with Down syndrome. This method was chosen because qualitative research is particularly useful when little is known about a specific phenomenon.

### Research Design

This study used interpretive phenomenology, which is a qualitative research design. Interpretive phenomenology was chosen as the method over descriptive phenomenology because interpretive phenomenology seeks to find shared meaning of experiences; whereas, descriptive phenomenology aims to describe experiences (Lopez & Willis, 2004). This design allowed dancers and family members to tell their story about an adapted dance program that met semi-weekly for 1½ hours for a total of 6 weeks.

### Sample/Population of Interest

The target population for this study was adolescents and young adults with Down syndrome. Inclusion criteria for participation as a dancer included: (a) individuals aged 12-30 years, (b) who were identified as having Down syndrome,

(c) who were willing and able to give informed consent or assent along with parental/guardian consent, and (d) who were willing and able to participate in the adapted dance program and miss no more than four dance classes. Exclusion criteria included (a) not meeting the above four criteria and (b) those who were already enrolled in dance classes. Family member inclusion criteria included any relative who was willing to take part in a focus group or telephone interview at the conclusion of the dance program.

### Selection of Subjects

Twenty dance participants were recruited for this study using a purposive sampling technique and snowballing. Dancers were recruited from the local community. Specifically, dancers were recruited from Down Syndrome Indiana, Best Buddies, a local children's hospital, and Special Olympics. Face-to-face recruitment, emails, and flyers were used to help identify eligible dancers. The recruitment flyer for the study can be found in Appendix B. Parents of potential dancers were asked to contact the researcher by phone or email to obtain further information about how to enroll in the study. Family members of dance participants were approached at the beginning of the dance program and offered the opportunity to participate in either a one-on-one interview or a focus group to discuss the meaning of the dance program from a family member's perspective.

## Procedures

### *Study Approval and Informed Consent*

Prior to recruiting participants for this study, permission was obtained from the institutional review board at Indiana University Purdue University Indianapolis. Before beginning the adapted dance program, the study was explained to both dance participants and their family members and their questions were answered. Adolescent dance participants, aged 12-17 years of age provided written assent with parental/guardian written consent. Adult dance participants aged 18-30 years of age provided either individual written consent or written assent with parental/guardian written consent. This was determined by discussing the consent/assent process with the accompanying parent/guardian on the first visit. Verbal consent was again obtained prior to the one-on-one interview. Family member participants provided written informed consent immediately before the focus group or prior to the one-on-one interview. Verbal consent was again obtained at the beginning of each focus group and one-on-one interview.

There were minimal risks associated with this study. Possible risks to dancers included musculoskeletal injuries such as ankle sprains during dance sessions. Additionally, both the dancers and family members may have felt discomfort when telling their story during an interview or focus group. To help minimize discomfort during interviewing, dancers and family members were informed that they could choose to not answer any of the questions during the

interview or focus group and/or withdraw from the study at any time with no consequences. The benefits of this study for dancers included acquiring unique motor skills via participation in a 6-week adapted dance program that supported physical health and wellbeing, social interaction with peers in a physical activity setting, and sharing their story about their lived experience in the adapted dance program. A benefit for family members was telling the story of their loved one's participation in the dance program.

All data for this study were kept in a locked and secured database. All interviews were transcribed verbatim and de-identified, and all names and locations were changed to pseudonyms.

### *Dance Program*

A 6-week adapted dance program was designed specifically for adolescents and young adults with Down syndrome. Dance classes met twice per week for 1½ hours each. The researcher served as the program director; there was a lead dance instructor, 4 assistant dance instructors, and 12 additional volunteers who assisted during each class. The large number of volunteers was needed to provide both modeling and social support for dance participants. It is important to note that the researcher for this study is knowledgeable about both rehabilitation and kinesiology, trained in dance, and trained in qualitative methods. She has a rich background in several dance techniques and believes that dance is a fun activity that everyone can participate



in, regardless of ability level or dance skills. Additionally, all dance instructors for this study were trained in adapted physical activity and also had experience teaching dance.

During the first 5 weeks of the dance program, each week there was a different theme, and the dance classes and dances styles corresponded to each theme. Week 6 included a dress rehearsal on the first night followed by a recital for family and friends on the second night. The weekly themes included Hip Hop, Fiesta, Country, Jungle, and Hawaiian. The themes paralleled different styles of dance including hip hop, Latin Cumbia, country line, African cultural, and Polynesian, respectively. All dances were choreographed and/or modified specifically for individuals with Down syndrome. This included the use of simple movements as opposed to complex movements, single-beat rhythm as opposed to half beat or double time, choreographing movements to words in the song rather than the beats, avoiding extreme ranges of movement in all joints, and avoiding all head movements.

To help increase adherence and minimize behavioral problems personal folders were used as a modified token economy system by positively reinforcing dancers' behavior (Bennett, et al., 1989; Cone & Cone, 2011). Each dancer had a personal folder in which they recorded their mood state before and after class and checked off each of the activities they accomplished during two breaks and at the end of each class. Dancers received stickers to use in their personal folder as long as they completed the dance class activities. The personal folders also

helped to build routine and keep dancers on task. Items from the personal folders can be found in appendix F.

At the beginning of the program all dancers received a t-shirt, dance calendar, and a CD with all of the recital songs. The logo for the t-shirts and the dance calendar can be found in appendices A and G, respectively. Additionally, each week the researcher emailed dancers and/or their family members a YouTube ([www.youtube.com](http://www.youtube.com)) link to the choreographed dances for that specific week. Dancers were encouraged to practice their dances at home using the CD and/or YouTube links.

Throughout the first 5 weeks dancers were learning choreography for dances that would be performed during the recital. During week 1 the dancers learned a hip hop routine to a popular pop song. During week 2 dancers learned a Cumbia routine that resembled Zumba Fitness ([www.zumba.com](http://www.zumba.com)). During week 3 dancers learned two country line dances, as well as a spiral dance where all the dancers connected hands and were led by the lead dance instructor in various lines, shapes, and spirals across the dance floor. During week 4 dancers learned an African style dance that was performed in a circle. In week 5 dancers learned a Polynesian style dance that included a variety of Hawaiian moves. An interpretive, unchoreographed dance was also included throughout the dance program that allowed dancers to “feel” the music and interpret the music by moving in whatever way they felt compelled. The song used for this dance was A Whole New World, from the movie Aladdin

(<http://disney.go.com/disneyinsider/history/movies/aladdin>). In total, dancers learned eight dances that they then performed in a dance recital for family and friends during the last dance class.

During each of the dances, the dancers were given props to use. Each prop corresponded to the five weekly themes. Week 1 dancers used a ribbon, week 2 dancers used maracas, week 3 dancers used bandanas, week 4 dancers used wooden sticks, and week 5 dancers used leis. At the end of the program the dancers received a personalized bag in which to take their dance props home.

All dance classes followed the same format to help dancers develop a familiar routine; this is important when working with individuals who have Down syndrome (Stanish & Frey, 2008). The format for each class included the following (a) review of the five basic dance class rules, (b) dance warm-up, (c) skill building activities across the floor, (d) break, (e) learn new dance choreography, (f) break, (g) dance activity stations and/or review prior dance choreography, and (h) cool-down and reflection activity for the dance class. Detailed lesson plans for each dance class can be found in appendix D.

At the beginning of each class the lead instructor reviewed the five basic rules. These five basic dance class rules were adopted from Dr. Theresa Purcell Cone, Associate Professor in the Department of Health and Exercise Science at Rowan University (<http://users.rowan.edu/~conet/>). The five rules were (a) do your best; (b) respect others; (c) be safe; (d) follow directions; and (e) share, be kind, and help others. These five rules were chosen because it is important to set

guidelines for class participation when working with individuals who have Down syndrome (Cone & Cone, 2005).

Immediately following the review of rules, the lead instructor led a warm-up called seat-to-feet that focused on basic body movements aimed at improving body awareness and rhythmic acuity (Bennett & Riemer, 2006; Jobling, et al., 2006). The same song was used to begin each class. Dancers always began on the floor finding the beat of the music with various body parts (e.g. pointing and flexing toes). Halfway through the song dancers stood up and continued finding the beat with other parts of the body (e.g. marching). By keeping the same song and activity, this helped to create a routine for the dancers. Following the first song, two additional songs/activities were included to complete the warm-up. For example, an activity called animal interpretation was used where dancers moved freely about the room interpreting various animals (e.g. elephant, monkey, etc.). A full list of warm-up activities is included in weekly lesson plans in appendix D.

The next activity, skill building, involved learning new dance steps and techniques by travelling back and forth across the floor (i.e. from one side of the room to the other side of the room). This allowed dancers to gain an awareness of their body in relation to space. This section was led by the lead dance instructor or one of the assistant dance instructors. The dance steps and techniques taught in this section corresponded to the weekly theme and were also part of the dance choreography that was

taught later in the class. For example, during country week dancers would walk down to one side of the room doing heel touches and then walk back to the other side doing toe touches. A more complete list of movements used during skill building can be found in the weekly lesson plans in appendix D.

Following this section was a break during which dancers were rewarded by checking off accomplished activities in their personal folder. During this time dancers could also get a drink of water or use the restroom.

The next section was choreography during which dancers learned new dance steps for one of the dances that would be performed in the recital. The lead dance instructor led this section. YouTube links to the weekly dances can be found in appendix E.

Following choreography there was another break during which dancers checked off the choreography section in their personal folder. Again, dancers were allowed to get a drink of water or use the restroom.

After the break the dancers were split into smaller groups and rotated through a series of fun dance stations that focused on learning dance technique, dance language, effort awareness, rhythmic acuity, and social interaction (Jobling, et al., 2006). These stations were led by the assistant dance instructors. An example of a station is Spaghetti Bowl where each dancer had a hula hoop that was placed on the ground (Cone & Cone, 2005). The focus of this station was to work on stiff and loose movements (i.e. effort awareness). When the dancer was instructed to step inside of the spaghetti bowl (i.e. the hula hoop), they were to move in loose movements to resemble cooked spaghetti. When

they were instructed to step outside of the spaghetti bowl, they were to move in stiff movements to resemble uncooked spaghetti. All station activities are included in the lesson plans in appendix D.

At the conclusion of each dance class, the lead instructor brought all dancers back together and led a cool-down activity, which was similar to the warm-up activities. Following the cool-down, a reflection activity was included that allowed the dancers to reflect on the session's activities. Examples included having each dancer say their favorite activity in the class, having dancers perform their favorite dance move from the class, or having dancers draw their dancing face on a sheet of paper.

As dancers moved from activity to activity the lead dance instructor used a visual activity schedule to show students the progression through the class activities (Cone & Cone, 2011). The schedule was written on the front mirror and included a list of all activities for the class. As each activity was completed the lead instructor moved a marker down the schedule until the end of class when all activities had been completed.

As stated in chapter two, there were a few additional special considerations that influenced the design of the adapted dance program. First, flexibility exercises were not included as most individuals with Down syndrome have an increased range of motion in joints when compared to individuals without Down syndrome (Angelopoulou, et al., 1999). Second, as stated above, head and neck movements were avoided because some individuals with Down syndrome are susceptible to atlantoaxial instability

(Pueschel & Scola, 1987). Third, although dancers were learning new dance steps and dance choreography, the lead dance instructor did not focus on dance technique. Rather, she focused on creative movement and did not stress that the moves be done correctly. Dance technique was mostly learned by the use of modeling with the lead instructor, assistant instructors, and other volunteers.

As stated previously, the dancers learned a total of eight dances that they performed in a dance recital for family and friends on the evening of the last dance class. At the conclusion of the dance recital, all dance participants received a certificate of completion and were recognized in front of all dance recital attendees. The dance recital announcement and certificate of completion can be found in appendices H and I.

### *Interviews*

Within 3 weeks of the final dance session, one-on-one unstructured interviews were conducted with the dance participants to explore their experience throughout the program. During this same time frame, small focus groups and one-on-one telephone interviews were also being conducted with the dance participants' family members. All interviews and focus groups were unstructured to allow dance participants and family members to share individual stories of their experience throughout the dance program. The researcher led all of the focus groups and one-on-one interviews. The lead dance instructor or an assistant dance instructor assisted during the one-on-one interviews with dancers. This was done to help dancers feel more comfortable by seeing a familiar face from

the dance program during the interview in hopes of helping dancers recall more of their experience.

### *Dancer Interviews*

Within 3 weeks of the dance program, dancers took part in one-on-one unstructured interviews until all eligible dancers were interviewed. All interviews were audio recorded and ranged from 5-30 minutes. Using interpretive phenomenology, the interviews were face to face in either a classroom adjacent to the dance studio or in the dancers' homes. The questions included open-ended, semi-structured statements to illicit the lived experience that had occurred throughout the adapted dance program. Specifically the researcher included the following statements in all dancer interviews: (a) "tell me about your experience in the dance program", (b) "tell me what it means to be able to dance", (c) "tell me how dancing makes you feel", and (d) "tell me about performing before your family and friends in the dance recital". As each dancer told their story, additional questions arose throughout the interviews that were used to probe dancers deeper into their individual experience. After all dancers had been interviewed, data were considered to be saturated. This was indicated by similar stories being told by dancers (Crist & Tanner, 2003).



### *Family Member Focus Groups and Interviews*

Interspersed among the interviews with the dance participants, one-on-one telephone and small focus group interviews with family members of participants were also conducted. The one-on-one telephone and focus group interviews were audio recorded and ranged from 30-60 minutes. The focus groups were held in a classroom adjacent to the dance studio. The focus groups used unstructured statements; however, some statements were based on themes that were identified during interpretive data analysis of the dancers' one-on-one interviews. Each telephone interview and focus group began with the statement "tell me about your family member's experience in the dance program". Responses to this statement were then used to ask more specific questions related to individual experiences.

### Methodology/ Data Analysis

Interpretive phenomenological methods were used to capture the perceptions of both dancers and their families. Interpretive phenomenology aims to identify the meanings of phenomena within a specific context. The method involved interpreting texts that included both the dance participants' and family member participants' stories.

Once interviews were completed they were transcribed verbatim, verified against the original recording, and de-identified. Audio recordings were destroyed once this procedure was completed. All transcripts were then read multiple times. De-identified data were analyzed for themes and patterns associated with

participants' with Down syndrome and the participating family members' perceptions of the meaning of the adapted dance program. Data analysis management was assisted by use of MaxQDA (MAXQDA VERBI GmbH), a computerized qualitative data management software. MaxQDA does nothing to analyze the data, but rather assists the researcher in organizing texts and themes.

The method of analysis in interpretive phenomenology actually begins during the interview. Based on what a dancer or family member said during interviews, the researcher quickly analyzed the information in order to ask follow-up questions, or probes that allowed the individual to delve deeper into their experience (Sloan, 2002). For example, if a parent said their child danced at home the researcher would ask a follow-up question such as "describe a time when this happened." This process would continue throughout the interview until recurring stories were being told. This was done to encourage interviewees to delve deep into their experience to find the true meaning of the dance program (Sloan, 2002).

Following the interviews, the researcher conducted a thematic analysis. This analysis involved carefully reviewing both dancers' and family members' stories, or transcribed interviews, to identify themes that were believed to be significant and meaningful to the study participants (Leonard, 1989). As stated in chapter two, hermeneutic interpretive analysis was used. The overall goal of this type of analysis is to discover meaning and to achieve understanding (Benner, 1985).

To help achieve neutrality, data analysis for this study was conducted by a team of individuals rather than a single researcher. Identifying themselves as members of the “Hermeneutic Circle”, the team consisted of the researcher, the researcher’s mentors, and additional graduate students from a variety of related disciplines. The lead dance instructor was also a reader of the narratives providing an additional perspective for the researcher. The interpretive process began with the identification of themes or “meaning”. In the first phase, individual narratives were analyzed separately (Crist & Tanner, 2003). Each narrative was read carefully and possible themes were identified. These identified themes were then grouped according to similarity within each individual narrative. The second phase involved the classification of shared experiences across all interviews (i.e. themes). This phase involved identification of shared themes across narratives. The initial grouped themes were combined with groups of themes from other narratives. By identifying the common experiences/themes among dancers and family members, shared meaning was identified. The qualitative data analysis software MAXQDA (MAXQDA VERBI GmbH) aided in the organization of themes across all transcripts. The final phase involved identifying strong examples, or paradigm cases, for each shared meaning/theme. This was achieved by re-reading individual narratives to identify individual stories that highlighted each theme. It is important to note that this process was not linear, and that the phases overlapped. After data analysis concluded, interpretations of the identified themes were made and a second literature review was conducted based on the themes that emerged (Crist & Tanner, 2003).

## **Chapter IV: Results**

The purpose of this study was to explore the lived experience of an adapted dance program. Using Heideggerian interpretive phenomenology, this study explored the experience of a 6-week adapted dance program, as perceived by both individuals with Down syndrome and their family members. The two specific aims of this study were:

1. To illuminate the experience of an adapted dance program as perceived by the dance participants.
2. To illuminate the experience of an adapted dance program as perceived by family members of the dance participants.

The overarching goal of interpretive phenomenology is to identify meaning and gain understanding of personal experiences. Heidegger used the term, *Dasein*, or being-in-the-world, to describe personal meanings of events or situations for individuals as they inhabit their own unique every day worlds. These results illuminate the experiences of dancers and their family members at the completion of a 6-week adapted dance program for individuals with Down syndrome.

While it was anticipated that the dance program would increase physical activity and social participation, the building of a connection of mind, body and soul for dancers and family members was not anticipated. The following describes the results of the study.

## Participants

A total of 20 dance participants and 22 family members (20 parents, 1 grandparent, and 1 sibling) were enrolled in this study. Age and gender of the 20 dancers, along with pseudonyms for the dancers and their family members are presented in table 1.

*Table 1: Pseudonyms and Age and Gender of Dancers*

<b>Dancer</b>	<b>Gender</b>	<b>Age (Years)</b>	<b>Family Member/s</b>	<b>Relation to Dancer</b>
Lindsay	Female	12	Cindy	Mother
Haley	Female	13	Barbara	Grandmother
Leslie	Female	13	Natalie	Mother
Sammy	Female	13	Margaret	Mother
Alan	Male	13	Tracy	Mother
Andrew	Male	13	Maria	Mother
Dale	Male	13	Sandy	Mother
Olivia	Female	14	Emilia	Mother
Stephanie	Female	16	Holly & Lauren	Mother & Sister
Jeff	Male	18	Pam	Mother
Morgan	Female	20	Evelyn	Mother
Rebecca	Female	20	Susie	Mother
Amy	Female	22	Kris & Bob	Mother & Father
Robert	Male	22	Sally	Mother
Jenny	Female	23	Laura	Mother
Chad	Male	23	Vicky	Mother
Ryan	Male	23	Alan	Father
Nicole	Female	28	Catherine	Mother
Eric	Male	29	Allison	Mother
Tyler	Male	29	Faith	Mother

Nineteen of the 20 dancers participated in a one-on-one interview. The one dancer who did not participate was found to be insufficiently verbal at the time of the interview; however, her mother participated in one of the small focus

groups. A total of seven small focus groups and two one-on-one phone interviews were held with family members.

### Adapted Dance: Connecting Mind, Body and Soul

Interpretive phenomenological analysis of interviews and focus groups revealed several themes related to participation in the dance program. The succeeding paragraphs will highlight the emerged themes related to the dancers' experiences as well as emerged themes related to the family members' experiences. However, it is important to first present the overall pattern that was identified by both dancers and family members. Thematic analysis across both dancer and family member interviews and focus groups revealed a common pattern, or shared meaning, of the dance program experience: adapted dance: connecting mind, body and soul. After reviewing all of the themes, it was interpreted by the researcher and confirmed by the Hermeneutic circle that dancers connected in many ways throughout the dance program with the most significant connection being a connection of mind, body and soul.

The overall pattern of adapted dance: connecting mind, body and soul was supported by a number of subthemes described below. Dancer interpretations revealed one theme – dancers experiencing a mosaic of positive experiences. Family member interpretations can be summarized in the following theme – family members experiencing pride in their loved ones. Pride in loved ones was expressed as (a) enjoying seeing loved ones develop new relationships, (b) observing increases in confidence and independence, (c)

recognizing an emerging ownership of skills, (d) identifying an increase in rhythm, and (e) underestimating potential in loved ones.

### *The Metaphor*

Before dancer and family member interpretations are discussed, the overall metaphor will be explained. Chapter two briefly mentions dance as an embodying experience. After reviewing all dancer interviews, it was apparent that all dancers were truly embodied and could express their self through dance. The following dance quote from dance choreographer Maestro Hector Zaraspe captures what many of the dance participants expressed during their interview (Dance Quotes: Movement & Expression):

“Music is the language of the soul,  
dance is the language of the body.  
Body and soul, music and dance conceive an  
instrument of expression through which the spirit  
communicates.”  
-Maestro Hector Zaraspe

This dance quote was used as the metaphor because it explains how the dancers were able to feel the music and dance to express who they are. The subsequent paragraphs will breakdown each of the individual themes and explain how they are all related to this metaphor. To better examine the two specific aims, the interpretations are separated into the dancer interpretations and family member interpretations.

Before discussing the connections with soul, it is important to define this term. Initially soul was defined as simply a spiritual or religious connotation. However, there are now multiple ways to define soul. In the current study soul

was defined as a person's inner being, heart or his/her essence. For example, the quote above highlights how dancers were able to connect with their inner being or essence while dancing throughout the dance program.

### Dancers Experiencing a Mosaic of Positive Experiences

Individuals with Down syndrome often live happy lives. A recent survey of individuals aged 12 and older who have Down syndrome revealed 99% of participants self-reported as being happy, 97% liked who they were, and 96% liked how they looked (Skotko, Levine, & Goldstein, 2011). Two studies examining self-awareness found individuals with Down syndrome to have high self-esteem and a positive sense of self (Cunningham & Glenn, 2004; Glenn & Cunningham, 2004). Dancers' reflections during interviews for this study revealed a very similar response in that all dance participants responded in a positive way. Dancers expressed their joy and happiness while dancing in a variety of different ways.

During each of the dancer interviews, the researcher aimed to reveal the lived experience of participating in the dance program. To explore this, she asked the dance participants four specific statements during the interviews. In particular, two of the statements revealed similar shared experiences. These two statements were "tell me what it means to be able to dance" and "tell me how dancing makes you feel". Although the questions are different, they revealed a shared meaning of an overall enjoyable experience for dancers. Dancers responded to these two statements with a mosaic of positive experiences.



### *An Overall Enjoyable Experience for Dancers*

The following are a few examples of common responses by dancers when asked these two statements. For example, Sammy, age 13, responded about being happy.

*“Happy...just exciting”,  
Sammy (13)*

Similarly, Andrew, age 13, discussed how he found enjoyment in the activity of dance.

*“Had fun...It was great dancing around”,  
Andrew (13)*

Stephanie, age 16, described how she not only had fun, but how she was exercising. She could notice that in addition to dancing, she was working out and using her muscles.

*“It was fun...toned up”,  
Stephanie (16)*

Eric, age 29, was one of the older dancers. He went on and on during his interview about how he just loved to dance because it was fun.

*“I like to dance...because it is fun...I just dance and  
have fun”,  
Eric (29)*

One of the older, higher functioning dancers – Nicole, age 28, talked about how dancing makes her feel better about herself and helps her when she is sad. She also explains how dance for her helps to relieve stress. Furthermore, she delves deeper and explains how she assumes a leadership role when she is dancing. This was very apparent throughout the dance program as Nicole would

help the younger dancers during the dance classes. She would help with things such as finding their spot during a dance and learning the specific dance moves.

*“...and it also makes you feel better about yourself...Happy, not stressed out, and helps me when I’m sad. I also learned leadership...I think being able to dance is always about helping each other”,  
Nicole (28)*

All of these responses illustrate how the dancers truly enjoyed themselves when they were dancing. It is also evident that dancing made them feel joyful or happy. Vicki Baum, an Australian novelist, once said “there are short-cuts to happiness, and dancing is one of them” (Dancing Quotes). This is very apparent in the dancers’ experiences in the adapted dance program.

As stated in the introduction, all individuals with Down syndrome have some degree of cognitive impairment. A few dancers were able to give more in-depth responses compared to other dancers. For example, Lindsay, age 12, responded specifically about one of the styles of dance (interpretive) and then explained in more detail how dancing made her feel.

*“I liked the interpretive dance...’cause, it’s cool and fun. Dancing made me pretty, very happy and pretty tired...and sweaty”,  
Lindsay (12)*

Lindsay was able to share more of her experience by explaining that dancing made her feel pretty. However, she also talked about how she was sweaty and tired. She also talked about how the interpretive dance was her favorite. This dance was a favorite for a lot of the dancers. In this dance the dancers used a ribbon and were told to interpret the music (A Whole New World, from the movie Aladdin) by moving in whatever way they felt compelled to move.

The dance quote below explains why this specific dance was a favorite for Lindsay and many others (Dance Quotes: Movement & Expression).

“Saying “I dance” would be an understatement  
and an insult to my life.  
I express. I move. I create.  
Every dance movement I make  
helps me orient myself in reality,  
my own emotions, and my own body.”  
-Joseph Baldock, professional dancer

This quote helps explain how the dancers felt during the interpretive dance. This dance allowed the dancers to let go and be free – to interpret the song by moving creatively in any way they felt compelled. Delving deeper into the meaning of this type of dance revealed that interpretive dance allowed the dancers to connect with their inner self and express their true being. The following dance quote by a professional dancer explains how dancing is not about having perfect technique (Dance Quotes: Dance & Spirituality). Rather, it is about feeling your soul. It may have been that the interpretive dance was an avenue for dancers to connect their mind, body and soul.

“Someone need not be perfect to be a great dancer –  
feeling a soul is more important than what the body  
can do.”  
-Marcia Haydee, professional dancer

For Amy, age 22, dancing was more than movement – it led her to become more comfortable with her true self, which is evidenced by her feeling of increased confidence. Confidence can be thought of as being comfortable with oneself and outwardly expressing their inner being or essence.

*“I think it gave me a chance to build my confidence  
back.”  
Amy (22)*

Haley, age 13, explained how she thought she was the most talented woman ever and how dancing in the recital made her work to be better for other people. This response coincides with the findings from three studies of self-perception in individuals with Down syndrome. On average, individuals with Down syndrome have high self-worth and a very positive self-awareness (Cunningham & Glenn, 2004; Glenn & Cunningham, 2004; Skotko, et al., 2011).

*“It was great...awesome, great...I’m the most talented woman ever...I had a good time working out...I worked my butt off when I did it...It made me try to be great for people”,  
Haley (13)*

Haley’s response was a little different from other dancers in that she focused more on how her dancing made other people happy (e.g. her grandmother). This, in turn, caused Haley to work harder to do a good job performing in the dance recital.

For the dance participants, the context of participation in an adapted dance program proved an interesting context when you think about Heidegger’s concept of embodiment. His concept explains how our bodies move and interpret the world we live in (Leonard, 1989). Dancing in itself has been described as an embodying experience. Researchers Block and Kissell (2001) stated “both literally and metaphorically, dance embraces what it is to be an embodied subject, what it is to know the world and to express our own presence here in the only way human beings can” (page 14). Additionally, the dance quote below by choreographer Ruth St. Denis really speaks one of the dancer’s explanations of her dance experience (Dancing Quotes).

“I see dance being used as communication between  
body and soul, to express what is too deep to find for  
words”

-Ruth St. Denis, modern dance pioneer/dance  
instructor

It is apparent in Rebecca's, age 20, interpretation of her dance experience that she feels the same way. Dance is an avenue for her to be herself, to connect with her soul, and to fully express her feelings. Furthermore, Rebecca was able to give a very meaningful response to these questions when she explained what dancing meant to her and how dancing made her feel. As you can see in the quote below, Rebecca states that dancing allowed her to feel her inner being, or as she defines it – her soul.

*“I had so much fun...and I love it...I love to  
dance...and I love spot light on me...feel like  
amazing, happy...it was fun...I feel like soul in  
me...it's just me...I can feel like grace or  
something...and pretty...and be myself to the music.”,  
Rebecca (20)*

A publication titled Dance Movement and Spirit discusses the importance of dance in connecting with the soul. LaPointe-Crump (2006) states “dancers absorb an exciting spiritual component that energizes them and makes them keenly aware of the raw materials of dance” (pg. 77). Rebecca's experience is just this. She feels her heart and soul within her and because of this she feels graceful. Her soul becomes one with the music when she dances and she is able to express her whole self. There is no doubt that Rebecca experienced the soulful component of dance that LaPointe-Crump talked about.

Heidegger introduced the concept of authenticity to explain that someone can become themselves existentially (Heidegger, 1962). To do this, however,

special circumstances must occur – one cannot be their authentic self at all times (Mansbach, 1991). For one to express their authentic self, they must be able to fully embrace the moment and connect with their soul. It is evident that dancing was an experience that provided an opportunity for individuals with Down syndrome to express their true authentic self. Dancing allowed dancers to be fully embodied and engaged in that moment in time, ignoring all outside distractions. The dance quote below explains why dance is a wonderful avenue for individuals to express their true authentic self (Dance Quotes: Movement & Expression).

“Learning to walk sets you free. Learning to dance  
gives you the greatest freedom of all: to express with  
your whole self the person you are.”  
-Melissa Hayden, professional dancer

This quote is powerful for dancers in that it tells the story of how a dancer is able to express his or her true self through movement. The dancers in the adapted dance program felt this freedom when they moved their bodies while dancing.

Although many of the dance participants had limitations in vocabulary and communication skills, some were able to interpret their experiences with the dance program. Others could not articulate and/or express such sophisticated ideas. Despite this, the dance program was something that had significance in their lives, and was a positive embodying experience that allowed them to connect their mind with their body through the movement of dance that further allowed a connection with their soul. Through dancing they were able to express their true authentic self.

### Family Members Experiencing Pride in their Loved Ones

Raising a child with a disability adds stress to families and often creates many challenges. When compared to families with other disabilities, families of children with Down syndrome tend to cope better and report less stress and fewer challenges (Cahill & Glidden, 1996; Hodapp, 2007). However, they do experience increased stress and challenges when compared to families without children with disabilities. Family member responses during focus groups and one-on-one interviews for this study were overall very positive. Family members expressed pride in their loved ones in multiple ways.

During each of the family member focus groups or one-on-one interviews, the researcher aimed to reveal the lived experience of observing a loved one's participation in the dance program. To explore this, she began by asking the family members to talk about their loved one's experience in the dance program. Answers to this statement prompted the researcher to ask deeper, more probing questions to learn more about individual experiences of family members.

The overall theme that emerged from family member interpretations was experiencing pride in their loved ones. This was demonstrated in the following ways (a) enjoying seeing loved ones develop new relationships, (b) observing increases in confidence and independence, (c) recognizing emerging ownership of skills, (d) identifying an increase in rhythm, and (e) underestimating potential in loved ones.

### *Enjoying Seeing Loved Ones Develop New Relationships*

The first way family members experienced pride was by enjoying seeing their loved ones develop new relationships. This revealed a shared meaning for family members – seeing their family member create new friendships. A survey of individuals with Down syndrome aged 12 and older revealed that 86% of individuals felt they could make friends easily (Skotko, et al., 2011). The adapted dance program provided a social opportunity that allowed dancers to easily form new friendships. The adapted dance classes were also good for the souls of parents who enjoyed seeing their children interacting in new ways.

Developing friendships and relationships is a very important developmental phase in any child's life. However, this can sometimes be a challenge for children who have disabilities and heartbreaking for their family members. This phase of development may be delayed or missing for individuals with disabilities. According to the Developmental Stages of Erik Erikson, a German Freudian ego-psychologist, developing intimacy is a very important step and should be the focus over isolation (English, 1999; Schlesinger, 2000). For example, a study of young adults with Down syndrome found friendship and intimate relationships to very important in the lives of those with Down syndrome (Smith, Christianson, Warren, Lemasters, & Patterson, 2001). It appears that family members felt the developmental needs of the dancers with Down syndrome in the current study were the similar as those of their peers. The following observations from family members showed the adapted dance program



was an opportunity for socialization with peers that can help their loved ones to achieve this important developmental stage.

Tracy, mom of Alan age 13, specifically enjoyed how Alan was interacting with so many other kids who had Down syndrome. This was the first opportunity for Alan to interact with such a large number of individuals with Down syndrome.

*“I think it was a great experience for him, he’s never been with that many kids with Down syndrome before.”*

*Tracy, mom of Alan (13)*

Furthermore, a recent study on leisure activity and friendship in children and adolescents with Down syndrome found one-third of the parents reported that their child had no friends. However, one-half reported their child as having two or more friends. Parents reporting two or more friends most often had children who were higher functioning allowing some independence. The overall findings of the research study suggested that children and adolescents with Down syndrome tend to live sedentary, self-contained lives (Oates, Bebbington, Bourke, Girdler, & Leonard, 2011). The adapted dance program was one way for adolescents and young adults to develop new friendships. In the present study, several family members reported an observation of an increase in social interaction and a development of friendships with other dancers as well as the volunteers.

Holly, mom of Stephanie age 16, was very excited for Stephanie to develop friendships with other children who have Down syndrome. This was also Stephanie’s first experience with such a large number of individuals who have Down syndrome.

*“It was wonderful for her to be with, actually, other kids with Down syndrome. ‘Cause she doesn’t know that many kids with Down syndrome. And, I was excited for her to be able to start relationships...”*  
*Holly, mom of Stephanie (16)*

The two quotes above highlight parental desires for programming that allows their child to be with other individuals with Down syndrome. This is an interesting perspective when thinking about traditional guidelines for adapted physical activity. Traditional guidelines suggest inclusive physical activity (Stanish & Frey, 2008). Could it be that parents actually desire the opposite?

Two parents discussed how they enjoyed seeing the interactions between all of the dancers. This is important to note because a lot of individuals with Down syndrome lack social participation (Oates, et al., 2011). This adapted dance program provided an avenue for social interaction with other individuals who have Down syndrome as well as individuals who do not have Down syndrome (i.e. the volunteers). Sally, mom of Robert age 22, really enjoyed seeing her son as part of a group.

*“It was fun to see them being made to feel part of group.”*  
*Sally, mom of Robert (22)*

As individuals with Down syndrome leave school, it is often hard to find community-based programming that provides an opportunity for social interaction (Jobling, Moni, & Nolan, 2000). The adapted dance program in this study provided an opportunity for dancers to connect with other individuals with and without Down syndrome. Similarly, a dance studio in Massachusetts, that holds a weekly adapted dance class, has a mission that includes improving social skills

for dancers. The director of the studio notes how the dance classes encourage social interaction and the development of new friendships. All dancers, volunteers, and instructors receive a t-shirt that states “Adaptive Dance, Friends for Life” (Bernstein, 2012). Vicky, mom of Chad age 23, delves a bit deeper into her observation and explains how exciting it was to see all of the kids interacting. She talked about the spiral dance where all of the dancers were holding hands and were led throughout the dance floor by the lead dance instructor. This experience was so meaningful to Vicki that it brought tears to her eyes.

*“Just to see the connection with all the kids. I thought that was cool. It made me cry.”  
Vicky, mom of Chad (23)*

#### *Observing Increases in Confidence and Independence*

One of the most common interpretations shared among family members was having a sense of pride while observing an increase in confidence and independence in their loved one throughout the dance program. For example, Tracy, mom of Alan age 13, discusses how both she and her mother noticed an increase in Alan’s confidence during the dance program. Dance provides an opportunity for individuals to be fully embodied in the moment allowing for the true self to surface. This may very well be demonstrated as an increase in confidence.

*“I think he had more confidence. And, sometimes my mom would notice more confidence”  
Tracy, mom of Alan (13)*

Similarly Kris, mom of Amy age 22, discussed how she thought Amy had gained confidence during the dance program. This is important, because Amy also talked about how dance provided her an opportunity to gain her confidence back. This is an example of triangulation in qualitative research (Annells, 2006). This is also an example of strong consistency in this qualitative research study. Similar stories were told by both mother and daughter.

*"I think it gave her more confidence."  
Kris, mom of Amy (22)*

Lauren, sister of Stephanie age 16, talked about how this was the first time she has witnessed her sister displaying full confidence in front of a crowd. It was a neat experience for Lauren to see her sister fully enjoying a performance while being her true self.

*"It's probably one of the few times that I've actually  
seen Stephanie in front of a crowd and smiling."  
Lauren, sister of Stephanie (16)*

Similar to confidence, several family members recognized an increase in independence in things such as getting ready for dance class, and also an increase in motivation to attend the dance classes compared to other physical activities such as Special Olympics. Several family members noted how the dancer would remind them about dance classes to make sure they didn't miss it, and a few of them discussed how some of the dancers still wanted to keep going to dance classes even after the conclusion of the dance program. Vicky, mom of Chad age 23, talks about how excited Chad was to write dance in his calendar. After the program had finished Chad would still ask his mom about returning to dance. This demonstrated how meaningful the dance program was for Chad.

*“Well, he really loved it. He was anxious to go... And, he really looks forward to it. He had to right down right away what days he was going...He still asks me every once in a while, can I go back to dance?”*  
Vicky, mom of Chad (23)

Similarly, Susie, mom of Rebecca age 20, states how upset Rebecca was when the dance program was over. This is to be expected, as Rebecca was the dancer who discussed feeling her soul during dancing. For Rebecca, dance was more than dancing – it was an escape, a time to connect with her soul and express herself fully.

*“She almost cried when it was over.”*  
Susie, mom of Rebecca (20)

Allison, mom of Eric age 29, talked about how Eric made dance a priority in his schedule and would skip other obligations to attend dance. This is another illustration of how much the dance program meant to dancers. It also speaks to the high adherence that occurred throughout the dance program. They truly looked forward to attending each and every class and were sad when the experience was over.

*“He was very motivated to participate. In fact, skipped other things so he could be sure to get here, so...”*  
Allison, mom of Eric (29)

Barbara, grandmother of Haley age 13, also talked about how Haley knew when it was time for dance. Haley was often ready to go early. Also, she speculated that Haley may transfer the skills she learned in the dance program to social events in the future. This is important, because social participation for individuals with Down syndrome can sometimes prove challenging. It is interesting to see that Haley’s grandmother believes the experience in the dance

program will transfer to future experiences. This can be seen as an example of applicability of the findings.

*“Haley enjoyed it. I mean at 4 o’clock she is saying, is it time to leave yet? I think Haley will have more fun at this year’s Down syndrome Christmas party, because she watches them dance...and, I think that maybe this year she’ll, she’ll go out and try it.”*  
Barbara, grandma of Haley (13)

Developing independence in individuals with Down syndrome is something that family members often struggle with (Rodrigues & Dupas, 2011). Although young people with Down syndrome report having friends, parents sometimes worry about whether or not their child will have the social skills and independence needed for such relationships with peers (Cuckle & Wilson, 2002). Increases in independence for children with Down syndrome is very important for families (Nunes & Dupas, 2011). Several family members in the present study explained how the adapted dance program provided an avenue that allowed dancers to increase their independence. This increase in independence is something that family members thoroughly enjoyed watching.

*“But, this was the first physical activity that I didn’t have to make her go to toward the end. Even Special Olympics. She was always ready and always knew it was scheduled...And her confidence level changed, we noticed over the course of the [dance program]”*  
Holly, mom of Stephanie (16)

Holly, mom of Stephanie age 16, goes beyond the increase in confidence and discusses how this was the first physical activity that Stephanie was actually motivated to attend. This is another example of high adherence to the dance program. Going beyond the motivation to attend the dance classes, Stephanie

was also motivated to do other physical activity. In fact, her mom notes how she started trying other physical activities.

*“And, she was on the treadmill last night at 11:30 at night. On her own. No one asked her to do it. So, I think she has confidence that she can be physically active.”*

*Holly, mom of Stephanie (16)*

This is important because physical activity can sometimes be a challenge for individuals with Down syndrome (Barr & Shields, 2011). The adapted dance program was specifically designed for individuals with Down syndrome and also followed the guidelines for adapted physical activity (Bennett, et al., 1989; Mahy, et al., 2010). This provided dancers a great opportunity to increase physical activity while increasing their social participation.

Emilia, mom of Olivia age 13, was thrilled to have Olivia excited about attending the dance classes and taking ownership in things such as getting her shirt ready. This was a very rewarding experience for Olivia because she had never experienced anything like this before with Olivia.

*“...and it was nice to see the independence as far as getting her shirt ready, you know...and, just secondly, knowing that she took ownership, I think was exciting for us. Because she was able to show them [the dances] with her siblings, and for her to say, “this is the way we do this dance,” you know... we have never experienced that before. I know she thoroughly enjoyed it because she reminded us about dance...First thing in the morning, Mom, you forgot dance. Olivia, no, we just started our day we haven’t forgotten.”*

*Emilia, mom of Olivia (13)*

Faith, mom of Tyler age 29, also touched on how much Tyler enjoyed the program. She also talked about how much pride he had in his dancing. He was also very upset that dance was over.

*“He loved it so much and he had to show everybody the video [of the dance recital] of it at the family vacation. And, yesterday we were doing his calendar for the month and he was not real happy with me that I did not put down dance on there. He wanted dance on there. So he absolutely loved it.”*  
Faith, mom of Tyler (29)

Sandy, mom of Dale age 13, talked about how Dale would listen to the CD of the dance songs when they rode in the car. He was similar to other dancers in that he also would count down the time until dance each week. This is another illustration of how much the dancing meant to the dancers.

*“We had the CD, had it in the car, and he loved having that and digging on the songs. He would just like count down how many days until [dance class]...”*  
Sandy, mom of Dale (13)

Similarly, Pam, mom of Jeff age 18, also talked about how Jeff was excited to attend the dance classes. Yet, another example of the motivation to attend the dance classes.

*“He liked it; he wanted to come every night.”*  
Pam, mom of Jeff (18)

### *Recognizing an Emerging Ownership of Skills*

The third way family members experienced pride was when they recognized an increase in ownership of the dance experience. Several family members talked about how the dancers would show the dances to family and



friends. Others discussed how it was an activity that they can do on their own. In general, family members were recognizing their loved ones experiencing an emergence of skills. Parents recognized this change at the end of the program. Their children had gained skills they did not know they had before. This is important for family members because this was most likely something new that they were observing in their family member. This experience allowed the dancers to take pride and ownership in something that they could do on their own. This in turn could explain the increase in maturity that Alan, dad of Ryan, age 23, expresses.

*"I think that provided some opportunities for growth in terms of maturity. Because, they had responsibility and they would take that responsibility on to make their own improvement."  
Alan, dad of Ryan (23)*

Margaret, mom of Sammy age 13, talked about how Sammy would show anyone and everyone the dances she had learned in the dance program. During the interview with Sammy she showed the researcher a picture of her performing one of the dances in a talent show at a local week-long camp for children with Down syndrome.

*"...she showed all of her brothers and sisters and neighbors and anyone [the dances]..."  
Margaret, mom of Sammy (13)*

Maria, mom of Andrew age 13, talked about how she enjoyed watching Andrew dance at home because it was a skill that he could do individually. It was a skill he could practice by himself at home. However, she also talked about how

Andrew's siblings would ask him to go to his room because he would just keep repeating the same songs over and over again – country was his favorite.

*"It's something they can do at home, something they can do on their own...played his CD in the kitchen computer. And, his siblings would go, "Andrew," 'cause a couple he was just pushing it to repeat. "All right all ready, take that to your room"...but he would take it to his room and he would dance and practice. And, that was kind of neat to see, 'cause the only other he will really practice on his own is basketball. So, I think it was neat that he had something else he could do on his own. More of an individual...Andrew absolutely loved it. I mean, he couldn't wait and he would tell me, it's Tuesday, I have dance tonight."  
Maria, mom of Andrew (13)*

#### *Identifying an increase in Rhythm*

A common observation from family members was an increase in rhythm that dancing provided. Individuals with Down syndrome often participate in adapted physical activity. However, dance is a physical activity that provides a unique experience where dancers must listen to and feel the rhythm in music (Sooful, et al., 2010). Family members discussed not only how their rhythm increased, but also how they could tell they were not just moving their bodies, but also using their minds. In addition to dancing to the rhythm of the music, dancers learned new dance moves during every class. These moves had to be memorized and recalled in each of the subsequent dance classes. Susie, mom of Rebecca age 20, noted how the dance program required dancers to use cognitive skills in addition to just moving. This is an interesting concept, because traditional physical activity does not typically require much mental stimulation.

*“And, it’s a physical activity that’s not just physical, it also includes, you know, you have to use your mind...”*

*Susie, mom of Rebecca (20)*

Very similar, Sally, mom of Robert age 22, also discusses how the dancing tapped into using cognitive skills. This is an interesting observation because dance has been shown to increase brain activity in areas such as memory and multitasking (Alpert, 2011).

*“...physically when anybody acquires something really new, I think it does something with your brain.”*

*Sally, mom of Robert (22)*

Barbara, mom of Haley age 13, also noted how she loved the exercise but also how much brain stimulation was going on. Dancing is a physical activity that requires individuals to memorize specific dance step and then later recall the order of the dance steps. This, in turn, challenges the brain in ways that traditional physical activity does not.

*“Oh, I think it is really good for them. Not only do they get the exercise, they had to use their little brains to think and they did make an effort. Plus the exercise. I think it’s great”*

*Barbara, grandma of Haley (13)*

Cindy, mom of Lindsay age 12, goes a step further and compares the dance program to physical therapy. This is family member observation is not surprising because dance is often used as a type of movement therapy for individuals with Down syndrome (Dupont & Schulmann, 1987).

*“And, I loved, you know, from a physical therapy standpoint, the activity they got, the movement they got. Fine motor skills.”*

*Cindy, mom of Lindsay (12)*

Tracy, mom of Alan age 13, notes how she observed an increase in rhythmic acuity in Alan. This is an important skill for all children to learn, and participation in a dance program may provide an avenue for increasing rhythmic acuity.

*“Alan doesn’t really clap in time to the music or anything, but I think it was beneficial to him to have body movement to the music. He probably grew in that way a little.”*  
Tracy, mom of Alan (13)

Holly, mom of Stephanie age 16, also commented how Stephanie had gained rhythmic acuity and could she could now clap to the beat of the music – a sign of rhythmic acuity.

*“Which I notice she’s better than that. Some of the clapping...there are things that she could not do before.”*  
Holly, mom of Stephanie (16)

### *Underestimating Potential in Loved Ones*

The final, and arguably the most meaningful shared experience of family members was that they underestimated their loved one’s potential. The dancers in the dance program far exceeded family member expectations. After reviewing the family member comments below, Heidegger’s fifth characteristic of personhood comes to mind – the person in time. This is important because Heidegger would argue that family members’ past experiences have some influence on expectations of their loved one who has Down syndrome. Heidegger’s fifth characteristic of personhood explains that a person’s past, present and future are inseparable. They all influence who a person is. For

example, Sally, mom of Robert, age 22, dwells on certain past experiences that for her have shaped a sense of what Robert cannot do rather than focusing on the positives of what he can do.

*“I don’t know. There’s, (sigh) there’s always a kind of a (sigh, sigh)...I don’t know how to say this, but a, you know, you are proud of them for what they have accomplished and you are also very aware of much they are not able to do, you know. So, watching a performance is kind of, nnnnnnnn. You know, like I didn’t invite anybody else...any of the friends of the family... And, so it’s not that I don’t think he can learn. But, you know, he learns slowly and building slowly.”*  
Sally, mom of Robert (22)

Similarly, Allison, mom of Eric, age 29, is reminded how she all too often underestimates individual capabilities in individuals with Down syndrome. She goes on to explain how she was surprised at Eric’s level of competence and will use this experience as a reminder not to avoid activities for him because she thinks he cannot do them. Although Allison’s remarks are similar to Sally’s, they differ in that Sally’s is more negative focusing on what Robert cannot do, whereas Allison’s is very positive focusing on what Eric can do. This is a very important concept in the field of adapted physical activity. Specialists in this area must focus on what an individual can do rather than what they cannot do. This is how activities are adapted – to what an individual can do.

*“And, as usual, another thing I always learn is I probably under-estimate what people can do. I was very impressed, and probably this is something Eric (29 y/o) knows how to do, and a lot of the participants could do, and maybe just had not had prior opportunities...I felt a sense of pride in Eric’s accomplishment and just in his enjoyment of the whole activity. That, it’s always fun to see people having a good time. Getting along and enjoying*

*something very difficult. And, again, I was surprised at his level of competence. So, it's a good reminder to just make sure you don't not do things because you don't expect people to be able to it."*  
Allison, mom of Eric (29)

Two additional parents talked about how they were amazed at how together the dancers were during the dance recital. All the way up until the day of the recital, both of these parents had their doubts, but were pleasantly surprised during the recital. Alan, dad of Ryan age 23, was surprised and the performance during the recital exceeded his expectations.

*"It was a joy for me because everybody was having a good time, and so how can you not be happy...I'm not surprised that when they were rehearsing, you know, they were picking up things, but I was really surprised at how you had them doing everything together the night of the performance...they did exceed my expectations."*  
Alan, dad of Ryan (23)

Cindy, mom of Lindsay, stated how she was very skeptical even up until the rehearsal for the recital. However, she too was surprised by the performance during the recital.

*"I mean, even the day before, when they were practicing, I was wondering how they would do in the recital, but really I mean, when the gun went off for the recital, they were right there and they put on a show...it was very heart-warming to watch."*  
Cindy, mom of Lindsay (12)

This underestimation of loved ones with Down syndrome by family members has been demonstrated once before in the literature. Bhattacharya and Sidebotham (2000) found that parents rated their child's behavior as more impaired when compared to primary care providers.

Heidegger's ontological perspective centers on what kind of human beings we are and how the world around us influences who we are. Intelligibility is a term that he used to help explain what makes Dasein (being human) different from non-humans (other forms of life and objects). He also states that we are thrown into our world and that our history is always before us and this limits our possibilities (Heidegger, 1962). How does Heidegger's philosophical perspective apply to humans with Down syndrome?

All people with Down syndrome have some degree of cognitive impairment, but their intelligibility of the world differs on a continuum from those with profound impairment who require constant care and supervision to those who are able to live communally with a caretaker and hold a job. We humans without Down syndrome have to be careful not to limit their possibilities. The family member responses above described how the dance program offered their adolescents and young adults possibilities.

### Summary

As stated above, the overall pattern from both dancers and family members was adapted dance: connecting mind, body and soul. In Heidegger's language, this is a three-fold. Just like past-present-future, the mind-body-soul three-fold cannot be separated from each other but are continually providing feedback and fore-grounding for both the dancers and their family members (Diekelmann & Ironside, 1998). The dance program provided dancers an opportunity to express their authentic self while experiencing moments of full

embodiment in the connection of their mind, body and soul. Alpert (2011) states “through the centuries the healing nature of dance and music were informally recognized for their mind-body restorative capability to make one “whole” again, but was never acknowledged formally until recently” (pg. 155). It is evident that this adapted dance program was a very meaningful experience for not only dancers, but also family members. While dancers experienced the connection of mind-body-soul, family members recognized the importance of this connection in their loved one.



## **Chapter V: Discussion and Conclusions**

The purpose of this study was to explore the lived experience of participation in an adapted dance program for individuals with Down syndrome and their family members. Using interpretive phenomenology, thematic analysis revealed an overall pattern of adapted dance: connecting mind, body and soul. The primary theme from dancer interpretations was expressing a mosaic of positive experiences. The primary theme from family member interpretations was experiencing pride in their loved ones. A total of five subthemes emerged from family members including (a) enjoying seeing loved ones develop new relationships, (b) observing increases in confidence and independence, (c) recognizing an emerging ownership of skills, (d) identifying an increase in rhythm, and (e) underestimating potential in loved ones.

The findings of this research illuminate the experience of an adapted dance program for individuals with Down syndrome. The results of this study not only describe what it means to be involved in an adapted dance program, but they also explain what the experience meant to both dancers and family members. As one can see, the overall experience was very positive for both dancers and family members. Dancers became embodied while dancing and were able to express their true authentic self. Family members experienced a great deal of pride in their family member by observing loved ones both during dance classes and at home. Parents in particular were enthused to see their child grow in terms of independence and ownership of an activity. Several

parents also noted how they loved the social interaction with other individuals who had Down syndrome. Furthermore, family members observed an increase in skills such as coordination and rhythmic acuity.

The findings of this research study can influence future dance opportunities for individuals with Down syndrome. Specifically, dance instructors, physical educators, and rehabilitation specialists who develop adapted physical activity programs for young people with Down syndrome will benefit. Knowing the lived experience of an adapted dance program for individuals with Down syndrome and their family members can help adapted specialists create future programming for this population.

## Discussion

Adapted dance for individuals with Down syndrome is a topic that has received minimal attention. Therefore, very little supporting literature exists related to the findings of this study. To the researcher's knowledge, this was the first study that explored the lived experience of an adapted dance program for adolescents and young adults with Down syndrome.

Phenomenological interpretation of narratives revealed an overall pattern of experiencing a connection of mind, body and soul. Both dancing and observing dance provided an opportunity for dancers and family members to be fully embodied in an experience. As stated in chapter one, dance itself has been explained as an embodying experience (Block & Kissell, 2001). A previous study on dance and the lived experience revealed one performer's experience as an

embodying experience of time and space that revealed a new world where the performance occurred (Davis, 2000). The results of this study showed similar findings for the dancers with Down syndrome.

The adapted dance program for this study was designed specifically for individuals who have Down syndrome (Cone & Cone, 2011; McHugh, 2007). Unknowingly, the dance program actually followed Laban's four movement analysis concepts of time, space, weight, and flow (Jobling, et al., 2006). Laban's concepts provided dancers a framework to learn dance. Further, his concepts enabled dancers to express a language of movement. One instance that this was observed was when dancers performed the interpretive dance to A Whole New World. This dance was not choreographed and dancers were encouraged to feel the music and use creative movement to express themselves through their dancing. One dancer in particular talked about how this dance was one of her favorites. Could it be that this dance allowed her to connect her mind, body and soul and express her true self?

Individuals with Down syndrome often experience lower levels of physical activity and social participation. Although this is the case, they still have the same needs for increased movement and social interaction. A recent study examined whether or not dance and music could be used as avenue means to help integrate individuals with intellectual disabilities into society. The results showed both dance and music as a positive medium to do so (Sooful, et al., 2010). The results of this study show similar results. The adapted dance program used both dancing and music to not only increase physical activity for individuals with Down

syndrome, but also to help increase social participation. Several family members discussed how they enjoyed seeing the interaction with other dancers and the volunteers. Furthermore, a few dancers discussed how they met new friends during the dance program.

A recent case study investigated a mother's perspective of a child with Down syndrome who was enrolled in a community-based performing arts program. The program included dance, singing, and acting. Both before and after the program the mother completed a survey to evaluate her child's physical, emotional, social, and school functioning. The results showed all categories expect emotional functioning to increase (Becker & Dusing, 2010). The results of this study show that family members observed similar changes in their children. Family member observations in the present study suggested dancers may have increased their physical and social functioning. Family members not only enjoyed seeing loved ones develop new relationships, they also recognized an emerging ownership of skills, and were able to identify a connection of mind-body-soul.

The overall pattern that emerged from both dancer and family member interpretations was adapted dance: connecting mind, body and soul. The mind-body connection was noted by several family members in that they observed their children having to use their mind to memorize and recall dance steps. The body connection was noted by several dancers discussing how dancing made them feel. Dancers were able to move their body to the music while using their mind. Further, one of the dancers was able to express how dancing allowed her to connect with her soul and created an environment for her to be herself. This in

particular highlights the whole connection of mind-body-soul. The mind-body-soul connection that dancing provides has been discussed a few previous articles. One of the articles focused on how dancing increases brain activity (Alpert, 2011). The second article notes the connection with soul/spirit that dancing can provide (LaPointe-Crump, 2006). The adapted dance program in the current study did just this. It provided an environment that allowed dancers to connect their mind, body and soul. This would then allow dancers to express what Heidegger would call the true authentic self (Heidegger, 1962; Mansbach, 1991). The third article discusses how dance is often used as a means to connect with the spirit during prayer for religious leaders (Bessette, 1999). Iris Stewart, a dance teacher who focuses on the mind-body-spirit connection of dance, stated the followed about dance (Dance Quotes: Dance & Spirituality).

“Dance is the essence of mystery.  
Through dance we experience a dimension that the  
linear mind is not structured to perceive.  
It may have been dance that enabled us to first  
conceive of existences beyond our immediate  
physical experience, thereby creating the concept of  
spirituality, of ‘God’.”  
-Iris Stewart

The fourth article recognizes how dance and witnessing dance provides a connection with mind, body and spirit (Mason, 2009). The article also discusses the term authentic movement from a dance therapy perspective (Pallaro, 1999). This notion of dance providing an experience of authentic movement coincides with Heidegger’s notion of the authentic self (Heidegger, 1962; Mansbach, 1991). The author states “I realized the power of this movement practice to transport me beyond the physical, to a more visceral experience and re-integration of my

mind/body/spirit, where I was able to engage in an inner dialogue with the subconscious” (pp. 26-27). Interpretation of Rebecca’s statement during her interview after the adapted dance program provided a very similar meaning.

*“I had so much fun...and I love it...I love to dance...and I love spot light on me...feel like amazing, happy...it was fun...I feel like soul in me...it’s just me...I can feel like grace or something...and pretty...and be myself to the music.”,  
Rebecca (20)*

Although individuals with Down syndrome may not have the cognitive ability when compared to individuals without Down syndrome, they are still able to connect with their mind, body and soul through the authentic movement of dance.

Although very little literature exists on adapted dance for individuals with disabilities, several dance studios and camps exist throughout the United States. For example, Camp Thunderbird is a physical activity and arts summer camp located in Dallas, Texas (Keglon, 2011). The program is an inclusive program that included campers with Autism Spectrum Disorder as well as other cognitive disabilities. The camp provided all sorts of physical activities, but also focused highly on creative movement, dance and music. It is important to note that programs such as this do exist. However, further research is needed to better evaluate how programs may influence individuals with disabilities and their families.

According to Heidegger, lived experiences about a specific phenomenon cannot be explored unless it is within its authentic context; and the past, present and future has an influence on every experience. However, based on the

researcher's interviews with the dance participants, it is noticeable that lower functioning adolescents and young adults with Down syndrome live almost completely in the present; the past is quickly forgotten, and they are incapable of thinking about the future. For example, one young man could remember almost nothing about the dance classes and program only 2 weeks after the program when he was interviewed. This was not true for a higher functioning young woman, who could remember the past and could contemplate the future (i.e. desire to participate in future dance opportunities). The past-present-future capabilities of the rest of the interviewees fell on a continuum in between these two participants. This awareness of living in the present has implications for the researcher and others in conducting future studies. They will likely optimize the quality of data by interviewing participants within a few days of the occurrence of interest in the location where it occurred.

That being said, one can look through the interviews with dancers and argue that although the conversations were simple, their meaning was rich in demonstrating the self-knowledge of most participants. In the following conversation with Rebecca, age 20, self-understanding is evident

*Researcher: What does it mean to be able to dance?  
What does that mean to you?*

*Rebecca: Meaning is it's just me. And, dance I can  
feel like grace or something.*

*Researcher: Grace?*

*Rebecca: Yeah. And, pretty. And, be myself to the  
music.*

The purity and innocence of Rebecca's response is a great expression of authenticity. Similarly, participant Andrew demonstrates self-awareness and authenticity when he reveals why he enjoys dancing.

*Andrew: It was great dancing around.*

*Researcher: It was great dancing around?*

*Andrew: And, I was by Haley to dance.*

*Researcher: You were by Haley to dance?*

*Andrew: Yes.*

*Researcher: Who is Haley?*

*Andrew: My girlfriend.*

Even though the conversations may appear to be simple, the researcher's use of reflective questioning allowed dancers the Freedom to express authentic answers. They were not encumbered by the pressure to produce an expected or pleasing answer, which might have been inauthentic, but were empowered to relate their story within their own comfort zone.

### Significance of Findings

This research is instrumental in advocating for opportunities for individuals with Down syndrome to experience dance as a social, physical and intellectual activity that results in learning and increasing social interactions. The research findings from this study should support future initiatives for dance programs that may influence a population that has limited access to physical activity and dance. The study's teaching strategies, dance activities, class procedures and sequences, and feedback techniques can be used by other professionals who teach individuals with intellectual disabilities. The results offer new insights into successful strategies that will encourage other dance educators and physical



activity instructors to initiate programs in schools and communities where programs do not currently exist. The study clearly addressed the needs for this population to experience dance as a meaningful way of learning, interacting socially, and expanding both physical and cognitive abilities.

### Evaluation of Quality Criteria

In qualitative research it is important to evaluate the quality of findings. For interpretive phenomenology there are four criteria that can be used to evaluate a study – trustworthiness, consistency, neutrality, and applicability. In this study trustworthiness was accomplished by only interviewing the dancers and family members. Trustworthiness was also attained by going into the interviews attempting to be as unbiased as possible with an open mind. Consistency was achieved by allowing dancers and family members to share their unique stories during interviews. Consistency was also found in the interpretation of narratives by using a team of researchers (i.e. the Hermeneutic Circle). Using the Hermeneutic Circle also helped achieve neutrality, along with the researcher recognizing her biases. The researcher has a rich background in dance, so it was imperative that she attempted to have zero preconceived notions and remain as neutral as possible during all interviews.

### Limitations of the Study

Although the researcher aimed to achieve validity in the present study, there will always be limitations in any study. The first limitation of this study is that

the results may not be applicable to all situations or all individuals with Down syndrome. Phenomenology seeks to identify the lived experience within specific contexts because the context of each experience highly influences meaning. The second limitation was a methodological limitation. Dancers were interviewed back to back with little time for the researcher to analyze transcripts. However, this could also be seen as a strength of the study because dancers had a fresh memory of the adapted dance program. If the interviews were conducted several weeks or months after the adapted dance program, dancers might not have been able to accurately reflect on their experience. The third limitation was the location of dancer interviews. The dancers were interviewed in a room adjacent to the dance studio that was unfamiliar to the dancers. This may have deterred dancers from being able to properly recall their experience while dancing in the dance program. If dancers had been interviewed in the dance classroom that was familiar to dancers it may have helped increase memory recall.

As stated in chapter one, all individuals with Down syndrome have some degree of cognitive impairment. One might speculate that Heidegger's third concept of personhood, a person as self-interpreting, may not apply to individuals who have a cognitive impairment. This was observed in the current study in that some dancers were able to recall experiences and contemplate the future; whereas, the more cognitively impaired the adolescent/young adult was the more s/he lived only in the

present. For example, some the dancers were hardly able to remember the recital after only 2 to 3 weeks. Therefore, the interviews should have been completed quickly and in as close to the environment of the dance classes and recital as possible. It is also possible that dancers were not able to understand questions or critically reflect on their experience. This study used an unstructured interview procedure, allowing modification of language as needed to facilitate the dancers' understanding and ability to respond to the questions. This allowed dancers to express themselves in their own words and in their own ways regardless of their cognitive skills. Furthermore, the researchers had prior experience with individuals who may have limited cognitive abilities and have successfully communicated with those individuals.

Another limitation of the study was that only family members were interviewed. In some cases, aids or assistants brought a dancer to the dance classes. In this situation, the family member interviewed may have had limited observation of their loved one throughout the dance program. To better capture the experience, future studies should consider including non-family member caregivers in interviews.

The last limitation is investigator bias. As stated above, the researcher has a background in dance and may have had preconceived notions about the experience of dance among individuals with Down syndrome. However, part of the phenomenological method is to make the researchers' positions known to themselves and each other so that preconceptions and biases can be addressed prior to and throughout the data gathering and analysis processes. Additionally,

the researcher was present at all of the dance sessions. Although she did not lead any of the sessions, the dancers and family members would have recognized who she was during the interviews. However, this could also be seen as a strength; recognizing the researcher may have helped dancers feel more comfortable during the interviews and possibly facilitate connections with the interviewer, which might have helped the dancers to better recall their experience in the dance program. Additionally, being at the dance sessions might have given the researcher ideas for questions that may not have otherwise been asked.

#### Suggestions for Further Research

As shown in chapter four, the dance program revealed several positive experiences for both dancers and family members. But perhaps one of the most significant interpretations came from a family member's observation. One parent in particular stated the following during one of the focus groups.

*"I think we all know you are going to be writing this up for your academic journals or whatever, but I would encourage you all to write something...because, you know, it would be nice if 100 communities started this next year and then 500 and then 1000 and...if people don't know about it, it's something; I don't know, maybe within your field, there might be many other places they would say, "Hey, we can do that, too." It's a wonderful program."  
Bob, dad of Amy (22)*

Researchers should take note of this comment because several parents also discussed how hard it is to find physical activity programming for adults with Down syndrome. The use of a community-based adapted dance program such

as the one in this study not only provides physical activity, but also an opportunity for individuals to interact with peers. Similarly, a few additional parents noted the following.

*“I totally enjoyed it because it’s hard, at her age, for her to find somewhere that she does fit in.”*  
Evelyn, mom of Morgan (20)

*“...especially when they get older, there’s not a whole lot for them to do.”*  
Natalie, mom of Leslie (13)

*“The older they get, the harder it is to find for Down syndrome’s to do.”*  
Susie, mom of Rebecca (20)

It is evident that parents of young adults with Down syndrome often struggle to find social opportunities for their children. The use of adapted dance proved to be an excellent means of providing this much needed community programming.

Further research is needed on similar programs being held in various locations throughout the United States in order to evaluate the applicability of the current study’s findings. Future studies should also include dancers with cognitive impairments other than Down syndrome. For example, one might speculate that a dance program for individuals with Autism Spectrum Disorder may reveal similar findings.

Future studies should also investigate the use of inclusive programming versus non-inclusive programming. Several parents noted the desire to have their child interact with others with Down syndrome. This desire should be further

evaluated and compared to the traditional adapted physical activity recommendations of inclusive programming.

Future research should also investigate coordination and rhythmic acuity before and after the dance program using a quantitative measure. Several parents noted this observation, but it will be important to evaluate if the observation is in fact statistically significant.

It is important to note that the researcher decided to continue the adapted dance program. One year following the first adapted dance program, the researcher directed the second annual adapted dance program – Live Laugh Dance Camp. All but two of the past dancers enrolled in the program for second year. Results of the second year of the Live Laugh Dance Camp are forthcoming.

The high adherence rate for the dance program should be noted and evaluated in future studies. Was the adherence high due to dancers having fun during the adapted physical activity of dance? Guidelines for adapted physical activity state that the activity should be fun (Stanish & Frey, 2008). Several of the dance participants noted during interviews how they had fun and how dancing made them feel happy. This should be further evaluated in future studies to determine if a connection exists between dance as a fun physical activity and adherence to adapted programming.

### Summary and Conclusions

This is the first study to explore the lived experience of an adapted dance program for individuals with Down syndrome. Therefore, it is

pioneering and forward thinking in determining the experience of an adapted dance program for individuals with Down syndrome and their family members. The results of this study showed an adapted dance program to be a very fun experience for dancers as well as very rewarding for family members. Future research should focus on a wider age range of dancers and hold adapted dance programs in different locations throughout the United States. Additionally, quantitative research should be used to evaluate whether coordination and rhythmic acuity actually do increase. Furthermore, individuals with other cognitive disabilities, such as Autism Spectrum Disorder, should be included in adapted dance programs to determine if the findings of this research study are applicable to other populations.

**Appendix A: Live Laugh Dance Logo & Picture of Dancers & Volunteers**



*Photography by Rebecca Ahaus*



## Appendix B: Recruitment Flyer



### FREE Dance Program

for young people with Down syndrome

#### The Procedure

You will be asked to complete assessments before and after the Dance Program. The dance program will include a variety of dances such as hip hop, country line, & more!

You will participate in 1.5 hour dance classes twice per week for a total of 6 weeks.

We will measure your balance and coordination before and after the program. At the end of the 6-weeks we will interview you about your experience.

#### The Study

People who have Down syndrome may benefit from participating in dance.

We want to invite you to participate in a 6-week Dance Program.

Our goal is to help you be physically active and learn new dances.

We are looking for young people who:

- \*Have Down syndrome
- \*Aged 12-30
- \*Not currently participating in dance classes
- \*Are willing to commit to 6 weeks of dance classes.

We will enroll 20 individuals in this study.

Study participants will receive a free t-shirt at the beginning of the dance program and a certificate of completion at the end.

For more information, call or email Rachel Swinford at 317-274-0875 or [rswinfor@iupui.edu](mailto:rswinfor@iupui.edu)

Note: If you participate in the study, a study number will be assigned. Your privacy will be protected.

#### Dance Program

Tuesdays and Thursdays  
6:30-8:00 PM  
IUPUI Natatorium  
Room PE 156—  
Auxiliary Gym

June 14th  
thru  
July 21st

Investigator: Rachel Swinford, MS  
IU School of Health and Rehabilitation Sciences  
1481 W. 10th Street, 11H  
Indianapolis, Indiana 46202

Study Site: IUPUI Natatorium

## **Appendix C: Dance Class Schedule & Class Rules**

### Dance Class Schedule

Review Rules

6:30-6:45 Warm-Up

6:45-7:00 Skill Building (e.g. across the floor)

Break

7:05-7:30 Dance Choreography

Break

7:35-7:50 Dance Activity Stations or Review Choreography

7:50-8:00 Cool-down & Reflection

### Class Rules\*

Do your best

Respect others

Be safe

Follow directions

Share, be kind and help others

*\*Adopted from: Dr. Theresa Purcell Cone <http://users.rowan.edu/~conet/>*

## Appendix D: Adapted Lesson Plans

Day 1 (Hip Hop)	Song	Activity	Notes
Warm up		Dance Ice Breaker	Name with a Dance move
	Move it	Seat-to-feet	Finding rhythm
	Shakeable you	Follow song instructions	
Across the Floor	Get this party started	Spiral dance along lines on the floor	
Across the Floor	Krunk & Krazy	Lateral movements	side steps, walking on toes, walking squats, heal taps, gallops, skips, side shuffles
Break	Urban grove	Repeat on multi directional lines	One groups and/or split in smaller groups
	Dancin' in the Streets		
Choreography	Baby	Teach verses & chorus of dance moves	
Break	Please Don't Stop the Music		
Stations	I Like It	Shoe Dance	Tempo training
	One Time	Dancing Dice	Group dance
	Somebody to Love	Dancing Shapes	Group makes shapes with bodies (as group or individually)
Cool Down/Stretch	A Whole New World	Ribbon Dance	Interpretive
	Wop Bop	Show new dance move learned	In small groups

Day 2 (Hip Hop)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Can you do it?	Follow song instructions	
	Balloon/hat stretch	Balloon/hat stretch	
Across the Floor	Krunk \$ Krazy	Lateral/multi directional movements Review	side steps, walking on toes, walking squats, heal taps, gallops, skips, side shuffles
	Route 66	Partner dancing	Two step and swing
Break	Dancin' in the Streets		
Choreography	Baby	Review	
		Teach beginning part and dance tunnel	Ribbon dance
		Review	
Break	Please Don't Stop the Music		
Stations	Dynamite	Cloud Dance	Interpretive
	Apologize	Spaghetti Bowl	Stiff and Loose movement/need hula hoops
	Stranger	Stop and GO	Holding positions/free dance
Cool Down/Stretch	We are all in this together	Hand Dance	
		Talk about favorite activity	Small groups and or large group

Day 3 (Fiesta)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Shakeable You	Follow song instructions	Use maracas
	Zumbandando	Follow the leader with Maracas	
Across the Floor	Que to Mueve Santa Que	Lateral/positional	Merengue (march, 2 step) Salsa (Front/back, side to side) Cumbia (Front/back, sleep leg, 2 step) Reggaeton (stomp, knee lift)
Break	Dancin' in the Streets		
Choreography	Fuego	Teach steps	
Break	Please Don't Stop the Music		
Stations	Zumbalicious	Percussion Dancing	Different moves for different beats (need sticks & maracas)
	Baila Pa Emociona	Low, Medium, High	Practice of different levels of dancing in space
	Shake Remix	Little Sally Walker	Try to incorporate new dance moves
Cool Down/Stretch	Zumba Lluvia	Interpretive Dance	Use any props (ribbons, sticks, shakers, etc.) to match music
		Dance Tunnel	w/ partner

Day 4 (Fiesta)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Can you do it?	Follow song instructions	
	Move your body	Follow song instructions	
Across the Floor	Que tu Mueve Santa Que	Lateral/multi directional movements Review	Merengue (march, 2 step) Salsa (Front/back, side to side) Cumbia (Front/back, sleep leg, 2 step) Reggaeton (stomp, knee lift)
	Hips Don't Lie	Partner dancing	Salsa
Break	Dancin' in the Streets		
Choreography	Fuego	Review	
	Baby	Review	
Break	Please Don't Stop the Music		
Stations	Shake Remix	Body Beats	Finding beats with different body parts
	We No Speak Americano	Bubble Dance	One person blows bubbles but when they pop-must freeze
	Shake your Bon Bon	Partner Mirror	Pretend you are a mirror with your partner (dance/exercises/stretch)
Cool Down/Stretch	We are all in this together	Hand Dance	
		I am...	Color in face on paper to describe feeling-tape to mirror

Day 5 (Country)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Cha Cha Slide	Follow song instructions	
	Good Time	Scarf Stretch	
Across the Floor	Cowboy Casanova Watermelon Crawl Boot Scootin' Boogie	Lateral/multi directional movements Review	Heel taps, toe taps, grape vines, side steps, basic turns, hip shakes walking on toes, walking squats, gallops, skips, side shuffles
Break	Dancin' in the Streets		
Choreography	You Belong With Me	Teach steps	
	Baby/Fuego	Review	
Break	Please Don't Stop the Music		
Stations	Copperhead Road	Spiral Dance	Need bandanas
	Sweet Home Alabama	Dancin' Dice	Group dance
	Cotton Eyed Joe	Verb Words	Personal interpretation of verb words
Cool Down/Stretch		Tiring Morning	Dance out waking up and walking down stairs
		Dance Tunnel	Big Group

Day 6 (Country)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Cupid Shuffle	Follow song instructions	
	Our Song		
Across the Floor	Little White Church	Lateral/multi directional movements Review	Heel taps, toe taps, grape vines, side steps, basic turns, hip shakes walking on toes, walking squats, gallops, skips, side shuffles
	Stuck like Glue		
	Save a horse ride a cowboy Sinwagon		
Break	Cotton Eyed Joe	Partner dancing	Basic Square Dance
	Dancin' in the Streets		
Choreography	God Bless Texas	Teach steps	
Break	Please Don't Stop the Music		
Stations	Life is a highway	Spiral dance	One big group
Review	Baby		
	Fuego		
	You Belong With Me		
Cool Down/Stretch	We are all in this together	Hand Dance	
		Favorite	Color in face on paper to describe feeling-tape to mirror



Day 7 (Jungle)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Animal Song	Act like the animal	
	Festival Music	Animal Stretches	
Across the Floor	Love Child	Lateral/multi directional movements	Begin reviewing previous steps, continue with turns and spotting
	Arabian Myth	Review	
	Latin Ritual		
Break			
	Dancin' in the Streets		
Choreography	Waka Waka	Teach steps	
Break	Please Don't Stop the Music		
Stations	I Want Some More	Parachute Circles	Practice moving in circles (rotation and forward/back)
	Sweat	Lion Dance	Dance out waking lion hunting for food, encourage facial expressions
	Oye	Emoticon Dance	Show emoticon, respond with dance/facial expression
Cool Down/Stretch	Multiple Songs	Music Change	Music starts faster and changes to slower and slower - Free dance/interpretive
	New York House	Show your favorite dance move	One big group

Day 8 (Jungle)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
	Festival Dance	Run through the Jungle	
	Love Child	Stick stretch-Yoga poses	
Across the Floor	Pam Pam Prrrum Sweat	Lateral/multi directional movements Review	Continue reviewing previous steps
Break	Dancin' in the Streets		
Choreography	Waka Waka	Review	
Break	Please Don't Stop the Music		
Review	Baby		
	Fuego		
	You Belong With Me		
Cool Down/Stretch	God Bless Texas		
	Waka Waka		
	A Whole New World	Circle Dance	Use scarfs/like spiral dance but in circle
		Talk about what dance move you like best	In small groups

<b>Day 9 (Hawaiian)</b>	<b>Song</b>	<b>Activity</b>	<b>Notes</b>
Warm up	Move it	Seat-to-feet	Finding rhythm
	Can you do it?	Follow song instructions	
	Feelin' Good	Mission Impossible	Try to keep object/lei on head during activities/stretches
Across the Floor	Jamaican Cumbia JaiHo Hella Decale	Lateral/multi directional movements Review	Review movements / add arm movements
Break	Dancin' in the Streets		
Choreography	Princess Pupuli	Teach steps	
Break	Please Don't Stop the Music		
Stations	The Art of Translation	Story Telling	Tell a story, dance out storyline
	Ain't No Mountain High Enough	Opposite	Walk/dance around - leader says opposite words (soft/hard,high/low) dancers act out one or the other
	Happy Together	Partner Mirror	Pretend you are a mirror with your partner (dance/exercises/stretches)
Cool Down/Stretch	We are all in this together	Hand Dance	
		I am...	Color in face on paper to describe feeling-tape to mirror

<b>Day 10 (Hawaiian)</b>	<b>Song</b>	<b>Activity</b>	<b>Notes</b>
Warm up	Move it	Seat-to-feet	Finding rhythm
	Shakeable you	Follow song instructions	
	Sport Song	Act out the sport	
Across the Floor	The Warlocks Fife	Lateral/multi directional movements	Review movements, combinations, ripple effects
	Catch the Moments as they Fly	Review	
	Tiny Bubbles		
Break	Dancin' in the Streets		
Choreography	Princess Pupuli	Review	
Break	Please Don't Stop the Music		
Review	Baby		
	Fuego		
	You Belong With Me		
Cool Down/Stretch	God Bless Texas		
	Waka Waka		
		Dancing with other senses	Lay on ground and close eyes, participants do activities/find body parts with eyes closed
		I am...	Color in face on paper to describe feeling-tape to mirror

<b>Day 11 (Rehearsal)</b>	<b>Song</b>	<b>Activity</b>	<b>Notes</b>
Warm up	Move it	Seat-to-feet	Finding rhythm
	Can you do it?	Follow song instructions	
Review all dances Determine additional activities based on needs			
	Spiral Dance		
	Baby		
	Fuego		
	You Belong With Me		
	God Bless Texas		
	Waka Waka		
	Princess Pupuli		
	Interpretive Dance		
Cool Down/Stretch		Little Sally Walker	Show your favorite dance move

Day 12 (Recital)	Song	Activity	Notes
Warm up	Move it	Seat-to-feet	Finding rhythm
Performance	Spiral Dance		
	Baby		
	Fuego		
	You Belong With Me		
	God Bless Texas		
	Waka Waka		
	Princess Pupuli		
	Interpretive Dance		
Present Certificates			
Cool Down/Stretch	We are all in this together	Hand Dance	Ask Parents to do to it with the dancers
Group Picture			

## Appendix E: Video Links

### *Down Syndrome Indiana: Live Laugh Dance Program 2012*

<http://www.youtube.com/watch?v=TQFTN27H9Lc&list=UUW81q0ZIG5KS3Vvn5H2RUnw&index=7&feature=plcp>

### *Adapted Dance Week 1: Hip Hop*

[http://www.youtube.com/watch?v=ra\\_JXbRF8ac&feature=plcp](http://www.youtube.com/watch?v=ra_JXbRF8ac&feature=plcp)

### *Adapted Dance Week 2: Latin Cumbia*

<http://www.youtube.com/watch?v=TqT2jcJr-OY&feature=plcp>

### *Adapted Dance Week 3: Country Line Dance 1*

<http://www.youtube.com/watch?v=D85UcLMBuSM&feature=plcp>

### *Adapted Dance Week 3: Country Line Dance 2*

<http://www.youtube.com/watch?v=tf4XAo8SOH4&feature=plcp>

### *Adapted Dance Week 4: African Cultural*

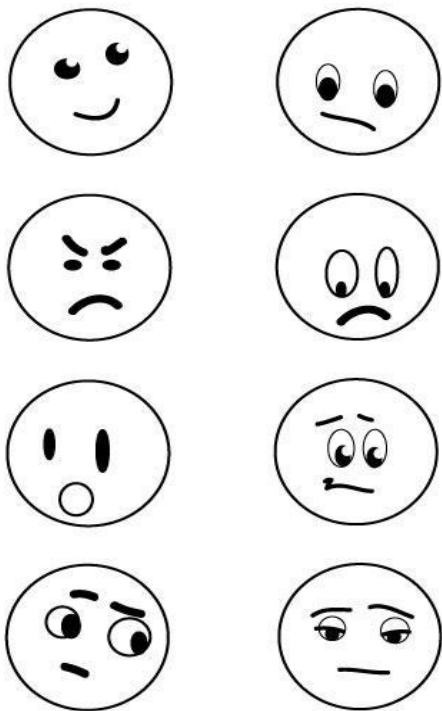
<http://www.youtube.com/watch?v=ej3B6poQFT8&list=UUC9iwzBAkbPuybC9O3QA4VA&index=3&feature=plcp>

### *Adapted Dance Week 5: Polynesian*

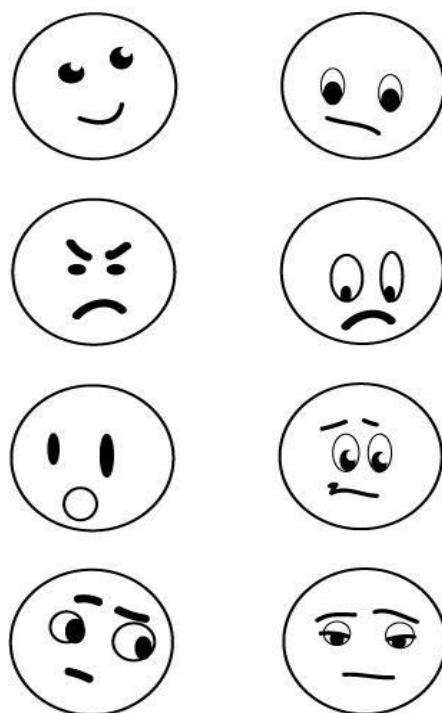
<http://www.youtube.com/watch?v=P39TvrQkJMM&feature=plcp>

## Appendix F: Personal Folder Information

Before  
Class



After  
Class





# CLASS CHECK ACCOMPLISHMENTS

	Warm-Ups	Skill Building	Choreography	Stations/ Review	Cool-Down	Reflection
Hip Hop 1						
Hip Hop 2						
Fiesta 1						
Fiesta 2						
Country 1						
Country 2						
Jungle 1						
Jungle 2						
Hawaiian 1						
Hawaiian 2						

## Appendix G: Dance Calendar



## Appendix H: Dance Recital Announcement



## Appendix I: Dancer Certificate of Completion



## References

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## CURRICULUM VITAE

**Rachel R. Swinford**

### EDUCATION

- PhD**                      **School of Health and Rehabilitation Sciences**  
Indiana University  
*Dissertation: Adapted Dance – Connecting Mind, Body and Soul*
- MS**                        **School of Physical Education and Tourism Management**  
Indiana University
- BS**                        **School of Physical Education and Tourism Management**  
Indiana University

### ACADEMIC APPOINTMENTS

- 2007-2008              **Visiting Lecturer, Department of Kinesiology**  
IUPUI, Indianapolis, IN
- 2008-2012              **Lecturer, Department of Kinesiology**  
IUPUI, Indianapolis, IN
- 2012-Present          **Lecturer & Director of Elective Program, Department of Kinesiology**  
IUPUI, Indianapolis, IN

### OTHER APPOINTMENTS

- 2003-2005              **Manager, Curves International, Indianapolis, IN**
- 2005-2007              **Graduate/Research Assistant, Department of Kinesiology, IUPUI**
- 2011-Present          **Group Fitness Instructor, Beech Grove Community Center, Beech Grove, IN**
- 2011-Present          **Dance Instructor, 8 Seconds Country Line Dancing, Indianapolis, IN**

### CERTIFICATIONS

- 2008-Present          **Health Fitness Specialist, American College of Sports Medicine**
- 2011-Present          **Zumba Basic 1, Zumba Fitness**

## PROFESSIONAL ORGANIZATIONS

2007-Present	American College of Sports Medicine
2007-Present	Indiana Association for Health, Physical Education, Recreation and Dance
2008-Present	American Alliance for Health, Physical Education, Recreation and Dance
2008-Present	Phi Epsilon Kappa National Fraternity

## HONORS AND AWARDS

2005	IUPUI Top 100 Student
2008-Present	Golden Key International Honour Society
2008	IUPUI Outstanding Educator Recognition
2009-2011	IUPUI Favorite Professor Recognition
2011	Indiana University Trustees Teaching Award
2012	Indiana University Trustees Teaching Award

## PROFESSIONAL SERVICE

2008-2010	<b>Dance Council Member</b> , Indiana Association for Health, Physical Education, Recreation and Dance
2010-Present	<b>Dance Council Vice President</b> , Indiana Association for Health, Physical Education, Recreation and Dance

## UNIVERSITY SERVICE

2010	<b>Boot Scootin' for Camp Brosius Getaway</b> , IUPUI Impact Campaign Kickoff Event
2010	<b>Choreographed and Taught Thriller Dance</b> , Office of International Affairs
2010	<b>Taught Line Dancing for an IUPUI Sorority</b> , Alpha Sigma Alpha Sorority
2011	<b>Taught Line Dancing for an IUPUI Fundraiser</b> , Be Haiti Student Organization
2011	<b>Get Off the Couch and Get Movin' Presentation</b> , IUPUI Student Health
2011	<b>Taught Line Dancing at IUPUI's Jagathon Dance Marathon</b> , IUPUI Jagathon
2012	<b>New Year, New You – Setting Wellness Goals Presentation</b> , IUPUI Student Health

## STUDENT SERVICE

2007-Present	Academic Advisor for Student-Athletes, Department of Physical Education
2008-Present	Faculty Advisor, School of Physical Education & Tourism Management Student Council
2008-2009	Faculty Advisor, IUPUI Hip Hop Dance Crew
2011-Present	Faculty Advisor, Line Dance IUPUI

## COMMUNITY SERVICE

2010	<b>Riley Dance Camp Volunteer Dance Instructor</b> , Riley Hospital at IU Health North
2010 & 2011	<b>Taught Line Dancing in Physical Education Classes</b> , Cathedral High School
2011	<b>Taught Dance to IPS Students enrolled in the Riley Health Club</b> , IU Health
2011	<b>Dance Instructor</b> , Stables Country Line Dancing
2011	<b>Taught Dance to Children at The Fitness Farm</b> , Children's Better Health Institute
2011	<b>A Night of Foot Stompin' Fun</b> , Community Church of Greenwood
2011	<b>Holiday Dance Class and Karaoke Party</b> , Down Syndrome Indiana
2011	<b>Fitness and Soccer Mission Trip, Kenya, Africa</b> , The Gathering Place Sports and Fitness
2011-Present	<b>Volunteer Group Fitness Instructor</b> , The Gathering Place Sports and Fitness
2012	<b>Guest Instructor for Rhythms &amp; Movement Course</b> , Marian University
2012	<b>Taught Line Dancing in Physical Education Classes</b> , Warren Central High School
2012	<b>Taught Line Dancing at La Plaza Summer Camp</b> , St. Gabriel Catholic Church

## COURSES TAUGHT

HPER E100: Clogging  
HPER E100: Line Dancing  
HPER E100: Fitness Walking  
HPER E100: Stress Reduction/Meditation Techniques  
HPER E121: Weight Training and Conditioning  
HPER L135: First Year Seminar in Physical Education  
HPER P205: Structural Kinesiology  
HPER P212: Introduction to Exercise Science

HPER P246: Performance/Teaching of Cardiovascular Fitness & Resistance Training  
 HPER P258: Activities for People with Special Needs  
 HPER P271: Lifetime Activities (Camp Brosius, Elkhart Lake, WI)  
 HPER P403: Theory and Practice of Cardiovascular Exercise  
 HPER P409: Basic Physiology of Exercise Laboratory  
 HPER P443: Internship in Physical Education  
 HPER R275: Dynamics of Leadership Development (Camp Brosius, Elkhart Lake, WI)

## PRESENTATIONS

2009	<b>Swinford, R.</b> Line Dancing 101. Presentation, <i>Indiana Association for Health, Physical Education, Recreation and Dance Regional Workshops</i> , Marion, IN & West Lafayette, IN
2010	Haggard, L., & <b>Swinford, R.</b> Hip-Hop & Country Too! Presentation, <i>American Alliance for Health, Physical Education, Recreation and Dance National Convention</i> , Indianapolis, IN
2010	Haggard, L., & <b>Swinford, R.</b> Midwest District AAHPERD Dance Gala. Choreographer and Performer, <i>American Alliance for Health, Physical Education, Recreation and Dance National Convention</i> , Indianapolis, IN
2010	Haggard, L., & <b>Swinford, R.</b> Country Beats Meet City Streets. Presentation <i>PE4Life Resource Conference</i> , Kansas City, MO
2010	<b>Swinford, R.</b> , Arthur N., Lazaro, J., Ferrell, A., Gerena-Perez, B., & Anderson, M. STEPS To Creativity. Presentation, <i>Indiana Association for Health, Physical Education, Recreation and Dance State Conference</i> , Indianapolis, IN
2010	Sanders, G., <b>Swinford, R.</b> , McCullough, T., & Walsh, K. Dance Council Mixers. Presentation, <i>Indiana Association for Health, Physical Education, Recreation and Dance State Conference</i> , Indianapolis, IN
2011	Keith, N., Culp, B., & <b>Swinford, R.</b> Campus and Community Physical Activity Partnerships to Promote Health. Presentation, <i>Coalition of Urban and Metropolitan Universities National Conference</i> , Indianapolis, IN
2011	<b>Swinford, R.</b> Country & Hip Hop Part II. Presentation, <i>American Alliance for Health, Physical Education, Recreation and Dance National Convention</i> , San Diego, CA

- 2011 **Swinford, R.**, Sanders, G., McCullough, T., Walsh, C., Kline, K., & Kerr, M. The Dance Council Presents Line Dances & Dance Mixers. Presentation, *Indiana Association for Health, Physical Education, Recreation and Dance State Conference*, Indianapolis, IN
- 2011 Kline, K., **Swinford, R.**, & Kerr, M. Fitness Line Dancing. Presentation, *Indiana Association for Health, Physical Education, Recreation and Dance State Conference*, Indianapolis, IN
- 2011 **Swinford, R.**, Kline, K., Plopper, A., Kerr, M., & Gutierrez, A. Adapted Dance: Creative Movement for All! Presentation, *Indiana Association for Health, Physical Education, Recreation and Dance State Conference*, Indianapolis, IN
- 2012 **Swinford, R.**, & Gutierrez, A. Experiences of individuals with Down syndrome who participate in dance, Poster Presentation, *American Alliance for Health, Physical Education, Recreation, and Dance National Convention*, Boston, MA
- 2012 **Swinford, R.**, Kline, K. Adapted Dance Class. *4-P Support Group National Conference*, Indianapolis, IN

## GRANTS

- 2009 **Co-PI, RISE to the IUPUI Challenge Curriculum Development Grant**  
*Redesigned a departmental internship course to include a service learning component: INShape IUPUI*
- 2012 **Co-PI, Indiana Association for Health, Physical Education, Recreation and Dance Advocacy Grant**  
*Title: Everyone Exercising Everywhere: Home exercise videos targeted towards individuals with cognitive disabilities.*

## PUBLICATIONS

1. **Stevens, R.**, & Bahamonde, R. (2006) Comparison of two methods of manual digitization on accuracy and time of completion. Proceedings of the XXIV International Symposium on Biomechanics in Sports, pp 680-684: Salzburg, Austria. July 14-18.
2. Meneghini, R., Smits, S, **Swinford, R.**, Bahamonde RE (2008). A randomized, prospective study of three minimally-invasive surgical approaches in total hip arthroplasty: comprehensive gait analysis. *Journal of Arthroplasty*, 23(6): 68-73.
3. **Swinford, R.**, Warden, S. 2010 Factors affecting short-term precision of musculoskeletal measures using peripheral quantitative computed tomography (pQCT). *Osteoporosis International* 21: 1863-1870.